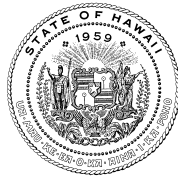


# **FAMILY CAREGIVERS: A SUMMARY OF NATIONAL AND LOCAL DATA**

**DECEMBER 2004**



**STATE OF HAWAII  
DEPARTMENT OF HEALTH  
EXECUTIVE OFFICE ON AGING**



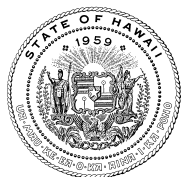
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(808) 586-0100**

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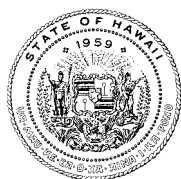
Phone: (808) 586-0100 ♦ Fax: (808) 586-0185

This report was prepared by Olga Geling, PhD and the Executive Office on Aging.

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## EXECUTIVE SUMMARY

Family caregivers are the predominant providers of long-term care nationally and in Hawaii, constituting the backbone of the long-term care system.

National estimates of the number of caregivers in the country range widely—between 5.9 and 52 million caregivers—depending on data source and the definition of a caregiver used.

Regardless of the definition of a caregiver used, considerable amount of national data clearly demonstrates the enormous value of the care provided by family caregivers. National data also shows the costs of caregiving to the caregivers themselves, in terms of negative impacts of caregiving responsibilities on caregivers' own health, employment, retirement, and in other aspects of their lives. Thus, there is growing effort nationwide to strengthen support of family caregivers and to better address caregivers' and care recipients' needs to enable persons with disabilities to stay in the communities.

Population-based, representative data on Hawaii caregivers and the older adults for whom they care, their demographics, needs, and financial costs, is virtually non-existent. This has to do with the fact that data on caregiving derives almost exclusively from certain national studies. As is common with other national studies, these national studies fail to represent Hawaii adequately, if at all.

Since 2003 however, the State Executive Office on Aging (EOA) has been sponsoring collection of a limited number of data elements on caregiving through the Hawaii Health Survey (HHS). And in 2000 the federal Administration on Aging sponsored two caregiving questions on the Behavioral Risk Factor Surveillance System (BRFSS). These data show that between 14% and 21% of Hawaii's adults provide regular care or assistance to persons aged 60 years old and older.



# DATA ON FAMILY CAREGIVERS

## NATIONAL DATA

### **PREVALENCE OF CAREGIVING: NATIONAL ESTIMATES OF THE NUMBER OF CAREGIVERS RANGE FROM 5.9 MILLION TO 52 MILLION CAREGIVERS.**

National estimates of the number of caregivers derived from the most commonly referenced caregiver prevalence studies range from 5.9 million caregivers to 52 million.

The estimated number of caregivers in the U.S. varies widely from study to study because there is no uniform definition of a caregiver.

### **PRIMARY AND SECONDARY CAREGIVERS**

Most people who need long-term care rely primarily on one or two key individuals.<sup>1</sup>

At least half of the caregivers identify themselves as primary caregivers, i.e. those who provide most of the care for the person who needs help (70 percent according to one study<sup>2</sup> and 51 percent according to another<sup>3</sup>).

### **MOST CAREGIVERS ARE EMPLOYED; MANY HAVE CHILDREN AT HOME.**

More than half of caregivers are employed outside of the home.<sup>4,5</sup> Approximately one in three caregivers has children under age 18 at home, and nearly one in five is both employed and has children at home.<sup>6</sup>

---

<sup>1</sup> Stone, R. *Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century*. New York, NY: Milbank Memorial Fund. 2000.

<sup>2</sup> Alecxih, L., Szeruld, S., & Olearczyk, B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C. Administration on Aging. 2002.

<sup>3</sup> The Henry J. Kaiser Family Foundation. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998*. 2002.

<sup>4</sup> Alecxih, L., Szeruld, S., & Olearczyk B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C.: Administration on Aging. 2002.

<sup>5</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>6</sup> Alecxih, L., Szeruld, S., & Olearczyk B.A. *Characteristics of Caregivers Based on the Survey of Income and Program Participation, National Family Caregiver Support Program: Selected Issue Briefs*. Washington, D.C.: Administration on Aging. 2002.

**TABLE 1: NATIONAL ESTIMATES OF THE NUMBER OF CAREGIVERS**

STUDY	ESTIMATED NUMBER OF CAREGIVERS	DEFINITION OF CAREGIVER AND CARE RECIPIENT
The Characteristics of Long-Term Care Users <sup>1</sup>	5.9 million caregivers	Family or friend providing help to a disabled elder (65+) living in the community with a need that has lasted or is expected to last 3+ months.
Informal Caregiving: Compassion in Action, Part II <sup>1</sup>	7 million caregivers	Provided care to an elder (65+) who needed assistance with everyday activities.
Characteristics of Caregivers Based on the SIPP <sup>1</sup>	9.4 million caregivers	"Unpaid care or assistance to someone [of any age] with a long-term illness or a disability during the past month."
Family Caregiving in the U.S., 1997: Findings From a National Survey <sup>1</sup>	22.4 million households (5 million of which provide care to someone with dementia)	Someone 18+ currently providing care or who had at some point in the past 12 months to a relative or friend who is aged 50+ to help them take care of themselves.
The Economic Value of Informal Caregiving <sup>1</sup>	24 million caregivers	Anyone aged 15+ needed or provided assistance with everyday activities due to a condition that lasted or was expected to last 3+ months.
The Economic Value of Informal Caregiving <sup>1</sup>	27.6 million caregivers	Need for or provision of personal assistance due to disability or chronic illness, aged 18+.
Behavioral Risk Factor Surveillance System (BRFSS) <sup>2</sup>	32.6 million caregivers	"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?"
Family Caregiving in the U.S., 2004: Findings From a National Survey <sup>3</sup>	44.4 million caregivers	Someone 18+ currently providing care or who had at some point in the past 12 months to a relative or friend who is aged 18+ to help them take care of themselves.
Informal Caregiving: Compassion in Action, Part I <sup>1</sup>	52 million caregivers	Aged 20+ providing "informal care" to a family member or friend of any age who is ill or disabled.

Source: <sup>1</sup> National Caregiver Alliance. *Fact Sheet: Side-by-Side Comparison of Family Caregiver Prevalence Studies*.

<sup>2</sup> Centers for Disease Control and Prevention (CDC). *Behavioral Risk Factor Surveillance System (BRFSS), 2000*.

<sup>3</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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## **FAMILY CAREGIVERS ARE THE PREDOMINANT PROVIDERS OF LONG-TERM CARE.**

Family caregivers provide most of the care to persons needing personal assistance, thus constituting the backbone of the long-term care system. Many family caregivers provide care over extended periods of time, for months and often years.

The majority (over three-quarters) of adults receiving long-term care at home rely exclusively on informal care, i.e., care provided by family members, friends, and volunteers.<sup>7</sup>

Even among adults in the community with substantial disabilities (limitations with three or more Activities of Daily Living), two-thirds rely exclusively on care rendered by family caregivers.<sup>8</sup>

Many family caregivers also provide hands-on assistance with various tasks, such as bathing and eating, to their family members or friends who are living in nursing home and other such settings.<sup>9</sup>

Many caregivers providing care for a family member over the age of 50 underestimate the length of time they will spend as caregivers: only 46% expected to be caregivers longer than two years. However, the average length of time spent on caregiving was close to eight years, with approximately one-third of respondents providing care for 10 years or more.<sup>10</sup>

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<sup>7</sup> Health Policy Institute, Georgetown University, analysis of data from the 1994-1995 National Health Interview Surveys on Disabilities, Phase II. Reported in: Thompson, L. *Issue Brief, Long-Term Care: Support for Family Caregivers*. Georgetown University Long-Term Care Financing Project, March 2004.

<sup>8</sup> *Ibid.*

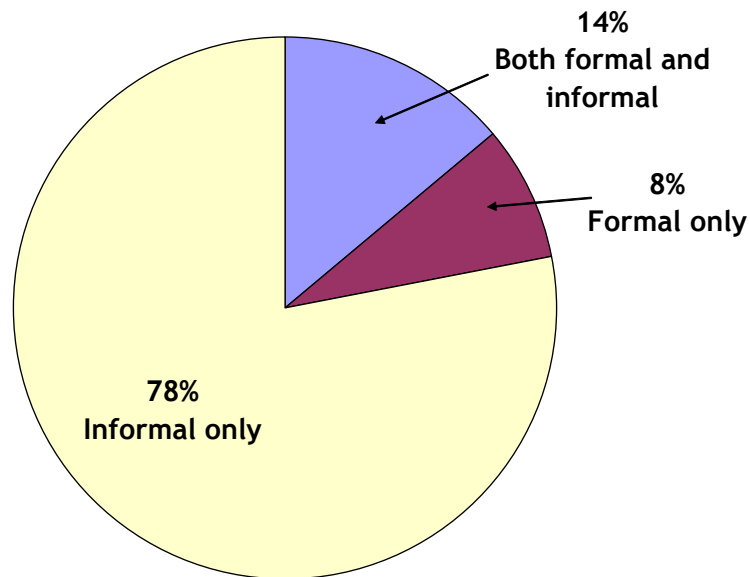
<sup>9</sup> Ross, M., Carswell, A., & Dalziel, W. Family Caregiving in Long-Term Care Facilities. *Clinical Nursing Research*, 10:347-363. 2001.

<sup>10</sup> MetLife. *Juggling Act Study, Balancing Caregiving with Work and the Costs of Caregiving*. Met Life Mature Market Institute. 1999.

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**FIGURE 1: DISTRIBUTION OF ADULTS RECEIVING LONG-TERM CARE AT HOME, BY TYPE OF CARE**

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Based on national data.

Note: Based on people age 18 and over who, because of disability or health condition, receive help from another person with Activities of Daily Living or Instrumental Activities of Daily Living (see Glossary for explanation of terms).

Source: Health Policy Institute, Georgetown University, analysis of data from the 1994-1995 National Health Interview Surveys on Disabilities, Phase II. Reported in: Thompson, L. *Issue Brief, Long-Term Care: Support for Family Caregivers*. Georgetown University Long-Term Care Financing Project, March 2004.

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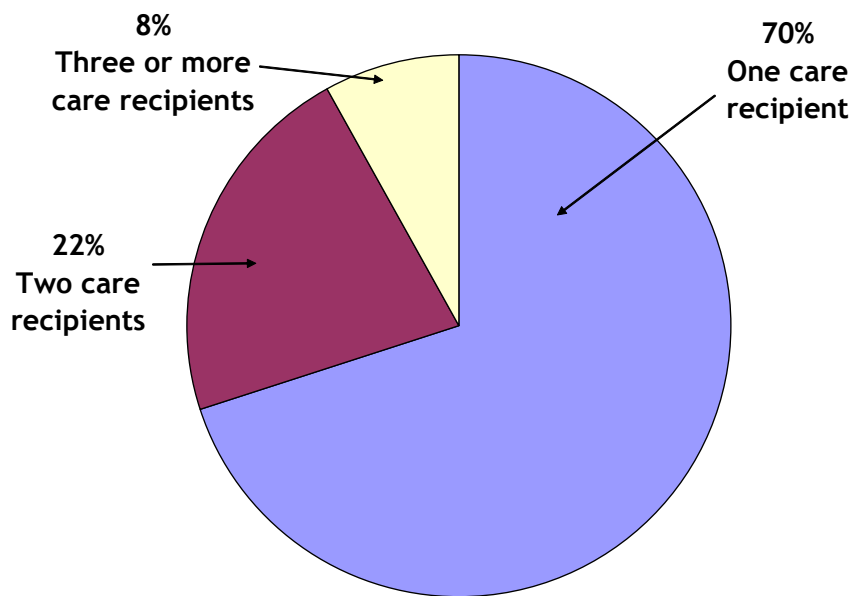
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## MANY CAREGIVERS CARE FOR MORE THAN ONE PERSON.

The majority of caregivers care for one person. However, three in ten caregivers report that they care for two or more persons.<sup>11</sup>

**FIGURE 2: NUMBER OF CARE RECIPIENTS**

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Based on national data.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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<sup>11</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

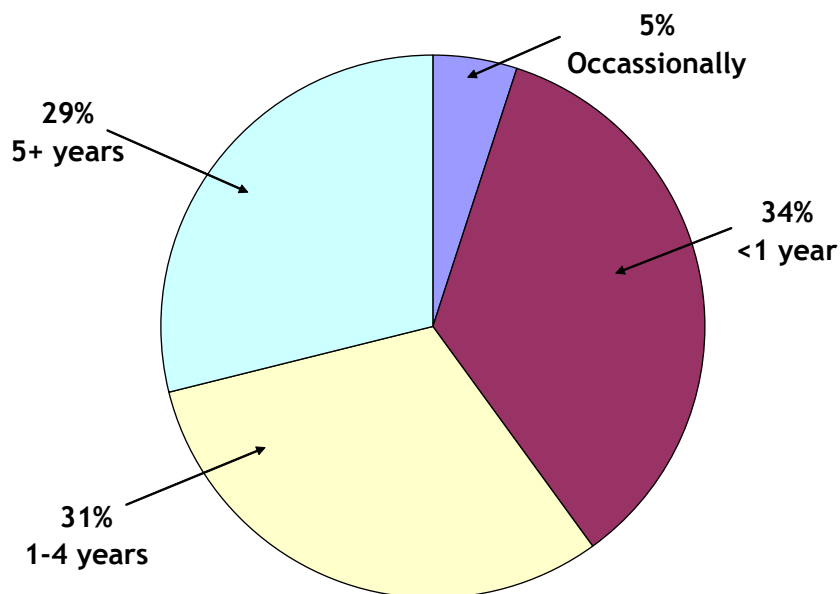
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## MANY CAREGIVERS PROVIDE CARE FOR SEVERAL YEARS.

According to a recent national study, the average duration of caregiving is over four years. Six in ten caregivers say they have provided care for a year or longer.<sup>12</sup>

**FIGURE 3: DURATION OF CAREGIVING**

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Based on national data. Percentages may not sum to 100% due to rounding.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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<sup>12</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

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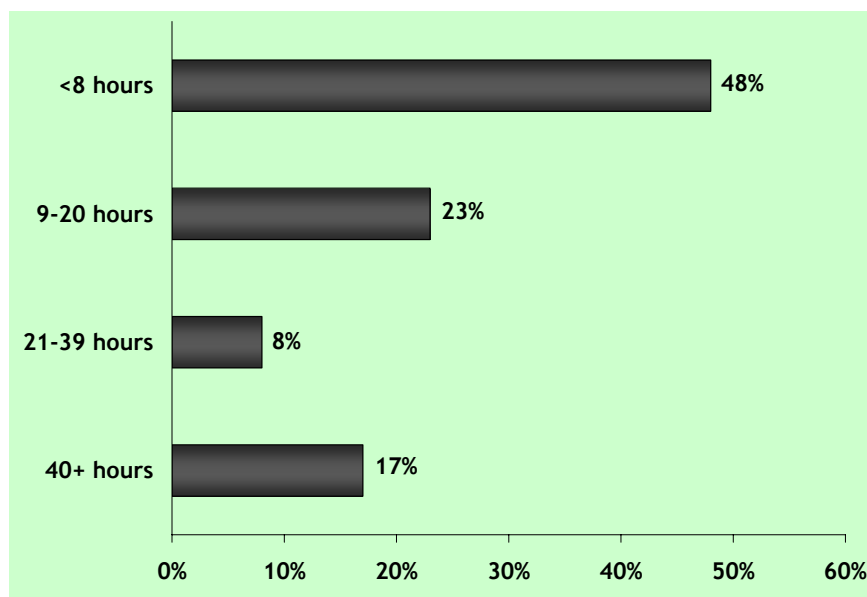
## LEVEL OF INTENSITY OF CAREGIVING VARIES.

Intensity of caregiving varies across caregivers, both in terms of the amount of time spent caregiving and duration and the kinds of care provided.<sup>13</sup>

According to a national study of caregivers providing personal care, more than half of caregivers provide at least eight hours of care a week.<sup>14</sup>

**FIGURE 4: HOURS OF CAREGIVING PER WEEK**

---



Based on national data.

Note: The Figure presents data on caregivers providing personal care to persons ages 18+, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

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<sup>13</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

<sup>14</sup> *Ibid.*

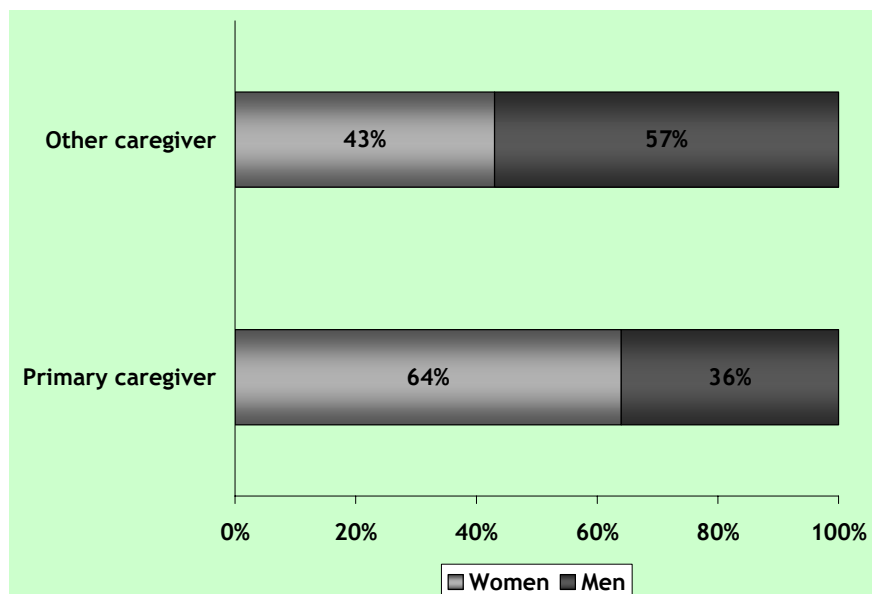
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## WOMEN ARE MORE LIKELY THAN MEN TO BE PRIMARY CAREGIVERS.

Nearly two-thirds of primary caregivers, i.e., those who provide most of the care for the person who needs help, are women; whereas men are more likely to be secondary caregivers.<sup>15</sup>

**FIGURE 5: GENDER OF PRIMARY AND OTHER CAREGIVERS**

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.

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<sup>15</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.



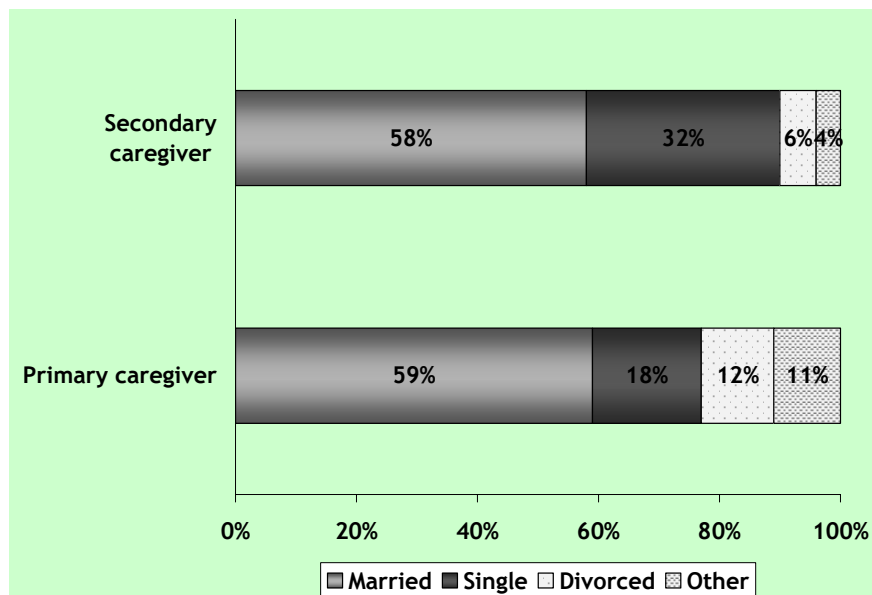
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## THE MAJORITY OF BOTH PRIMARY AND OTHER CAREGIVERS ARE MARRIED.

The majority of both primary and other caregivers are married. A higher proportion of secondary than primary caregivers have never been married.<sup>16</sup>

**FIGURE 6: MARITAL STATUS OF PRIMARY AND OTHER CAREGIVERS**

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.

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<sup>16</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.

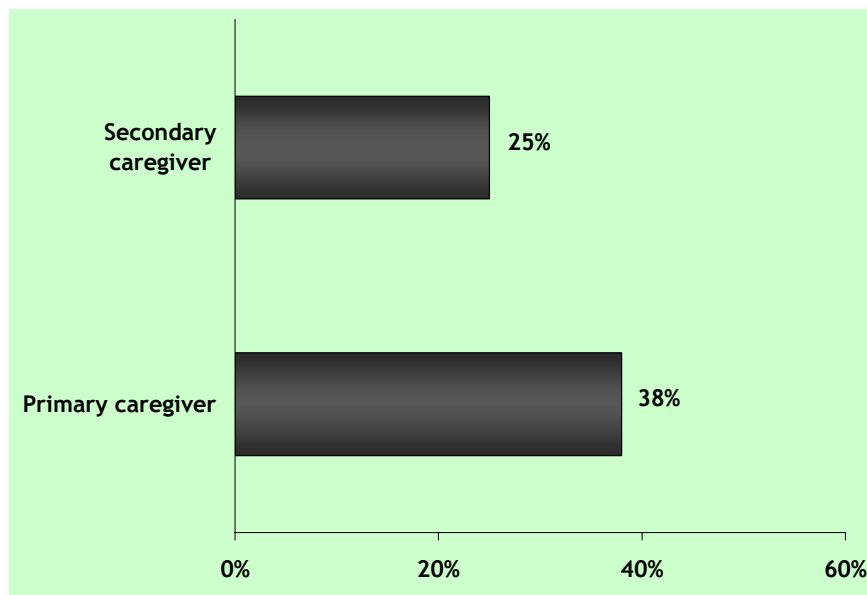
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## MANY PRIMARY CAREGIVERS HAVE SERIOUS HEALTH PROBLEMS THEMSELVES.

Many primary caregivers, who are generally older than other caregivers, have serious health problems themselves.<sup>17</sup>

**FIGURE 7: PRIMARY AND OTHER CAREGIVERS WITH SERIOUS HEALTH PROBLEMS**

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Based on national data.

Source: The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.

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<sup>17</sup> The Henry J. Kaiser Family Foundation, *et al.* *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective*, 1998. 2002.

## DATA ON FAMILY CAREGIVERS

### HAWAII DATA

In Hawaii, estimates of prevalence of caregiving, i.e., the percent of the adult population who are caregivers, and the number of caregivers derive primarily from two data sources:

- Behavioral Risk Factor Surveillance System (BRFSS), year 2000
- Hawaii Health Survey (HHS), year 2003.

Both sources use the definition based on the question that was included in the BRFSS for year 2000 nationally by the U.S. Administration on Aging. Thus, all of the Hawaii estimates presented below are based on this definition (unless stated otherwise):

*"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?"*

**AN ESTIMATED 14% TO 21% OF ADULTS IN THE STATE OF HAWAII PROVIDE REGULAR CARE OR ASSISTANCE TO A PERSON AGED 60 YEARS OR OLDER.**

**TABLE 2: PREVALENCE OF CAREGIVING IN HAWAII**

	SOURCE OF DATA	
	BRFSS 2000 <sup>1</sup>	HHS 2003 <sup>2</sup>
State	14%	21%
County		
Honolulu	14%	21%
Hawaii	14%	21%
Kauai	13%	21%
Maui/Kalawao	13%	20%

**TABLE 3: ESTIMATED NUMBER OF CAREGIVERS IN HAWAII**

	SOURCE OF DATA	
	BRFSS 2000 <sup>1</sup>	HHS 2003 <sup>2</sup>
State	126,598	192,390
County		
Honolulu	95,261	137,501
Hawaii	14,128	24,781
Kauai	5,631	9,579
Maui/Kalawao	11,578	20,529

Based on Hawaii data.

<sup>1</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

<sup>2</sup> Hawaii State Department of Health. *Hawaii Health Survey. 2003.*

## PREVALENCE OF CAREGIVING IS REMARKABLY SIMILAR ACROSS DEMOGRAPHIC AND SOCIOECONOMIC GROUPS.

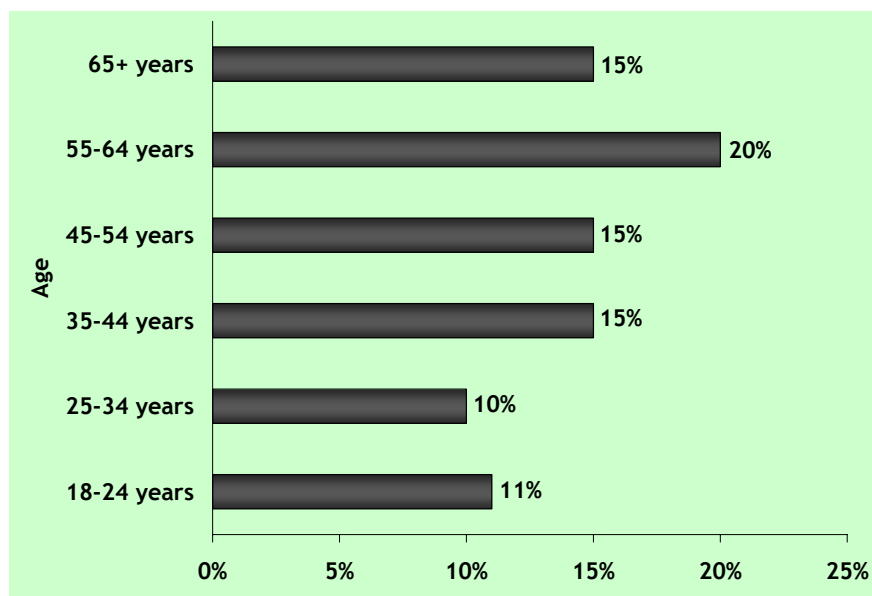
Overall, persons in different demographic groups and with different socioeconomic characteristics exhibit a remarkably similar likelihood of being caregivers.

(See CAREGIVERS BY COUNTY section for county data.)

### PREVALENCE OF CAREGIVING BY AGE

Persons below their mid-30s are least likely to be caregivers. Approximately one in ten Hawaii residents in that age group say that they provide regular care or assistance to someone 60 years old or older. Persons in the 55-64 age group are most likely to be caregivers, with approximately one in five persons saying that they provide care or assistance to someone 60 years old or older.

**FIGURE 8: PREVALENCE OF CAREGIVING BY AGE**



Based on Hawaii data.

Note: This figure represents the percent of respondents in each age group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study. Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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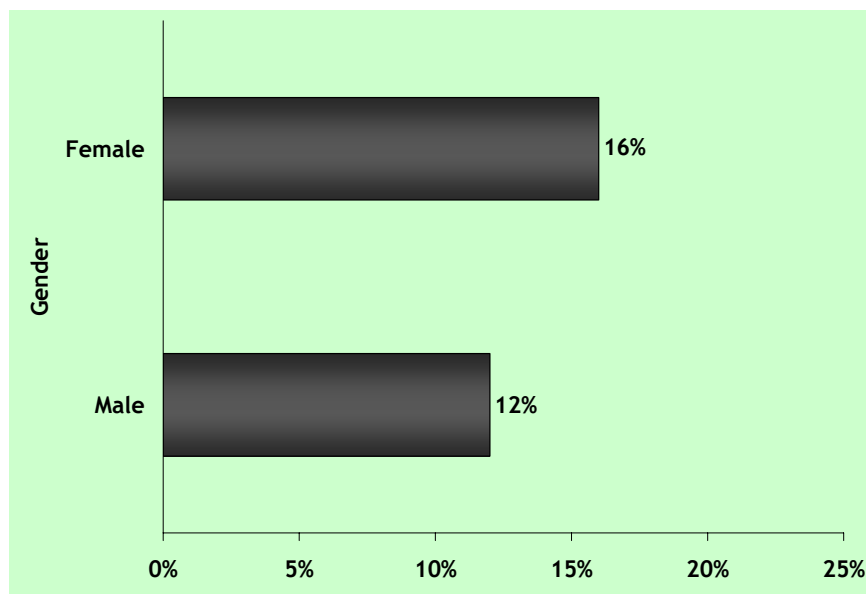
## PREVALENCE OF CAREGIVING BY GENDER

Similar proportions of men and women (12% and 16%, respectively) report that they provide care or assistance to someone 60 years old or older.

Although men are almost as likely as women to report that they provide care or assistance to an elderly person, several national studies have found that women are more likely than men to be primary caregivers rather than secondary caregivers, and that women are more likely than men to provide caregiving of higher intensity and frequency.<sup>18,19</sup>

**FIGURE 9: PREVALENCE OF CAREGIVING BY GENDER**

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Based on Hawaii data.

**Note:** This figure represents the percent of male and female respondents who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

**Source:** Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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<sup>18</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>19</sup> The Henry J. Kaiser Family Foundation, et al. *The Wide Circle of Caregiving: Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective, 1998.* 2002.

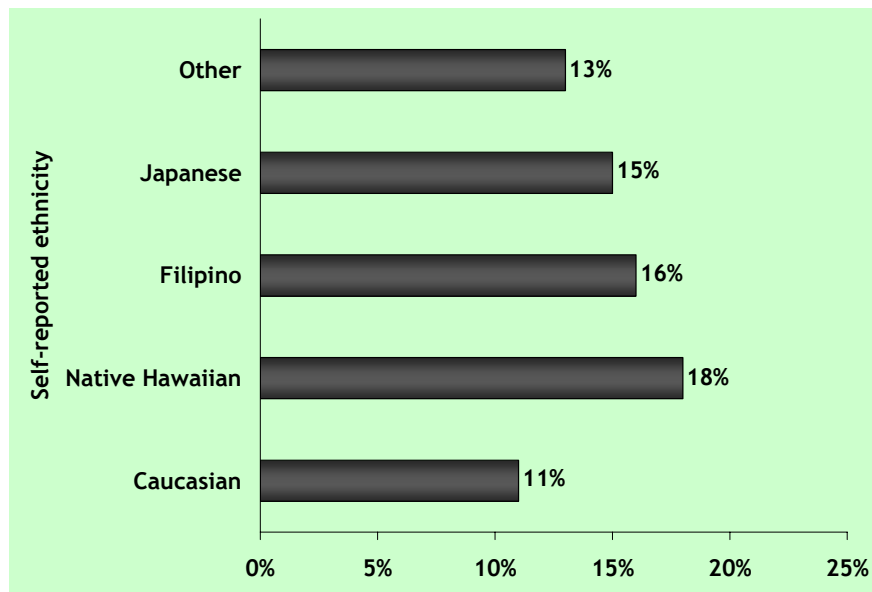
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## PREVALENCE OF CAREGIVING BY ETHNICITY

Among the different ethnic groups in Hawaii, Native Hawaiians are most likely to provide care or assistance to an elderly person (18%); Caucasians are least likely to provide care or assistance to an elderly person (11%).

**FIGURE 10: PREVALENCE OF CAREGIVING BY ETHNICITY**

---



Based on Hawaii data.

Note: This figure represents the percent of respondents in each ethnic group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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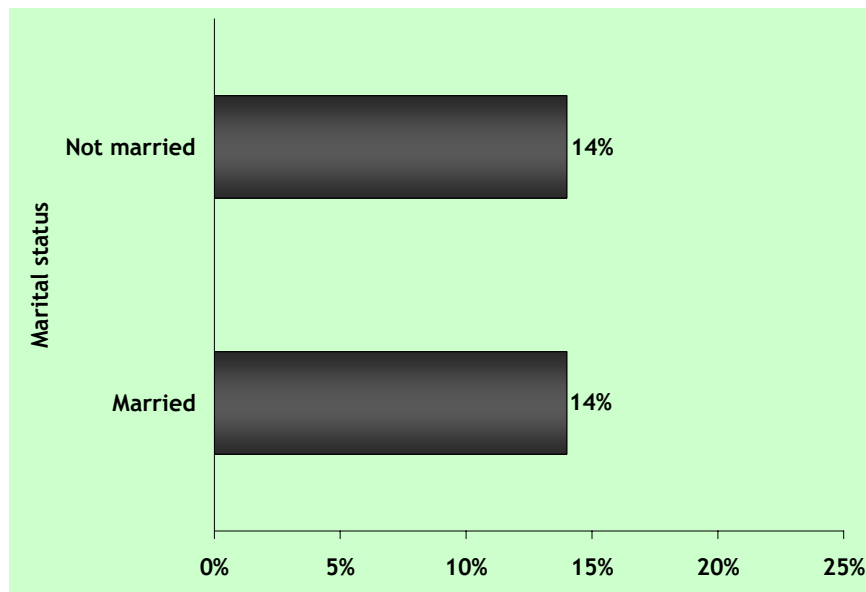
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## PREVALENCE OF CAREGIVING BY MARITAL STATUS

Married persons are as likely to provide care or assistance to an elderly person as their unmarried counterparts (approximately 14% of married and unmarried persons are caregivers).

**FIGURE 11: PREVALENCE OF CAREGIVING BY MARITAL STATUS**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each marital status group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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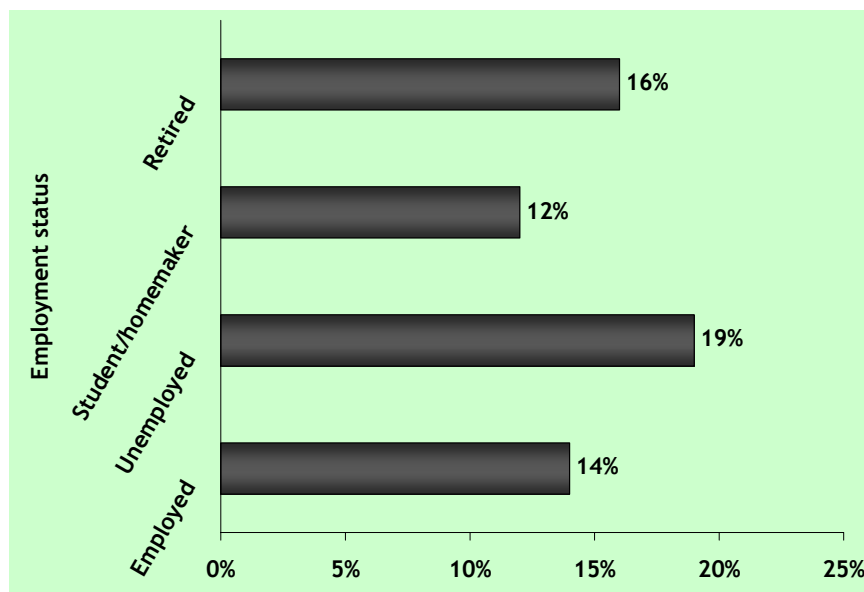
## PREVALENCE OF CAREGIVING BY EMPLOYMENT STATUS

A higher percent of unemployed than employed persons say that they provide care or assistance to an elderly person.

This rate of unemployed caregivers is consistent with findings of national studies that some caregivers resort to quitting their jobs or altering their employment arrangements to accommodate their caregiving responsibilities.<sup>20</sup>

**FIGURE 12: PREVALENCE OF CAREGIVING BY EMPLOYMENT STATUS**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each employment status group who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

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<sup>20</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers.* Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.

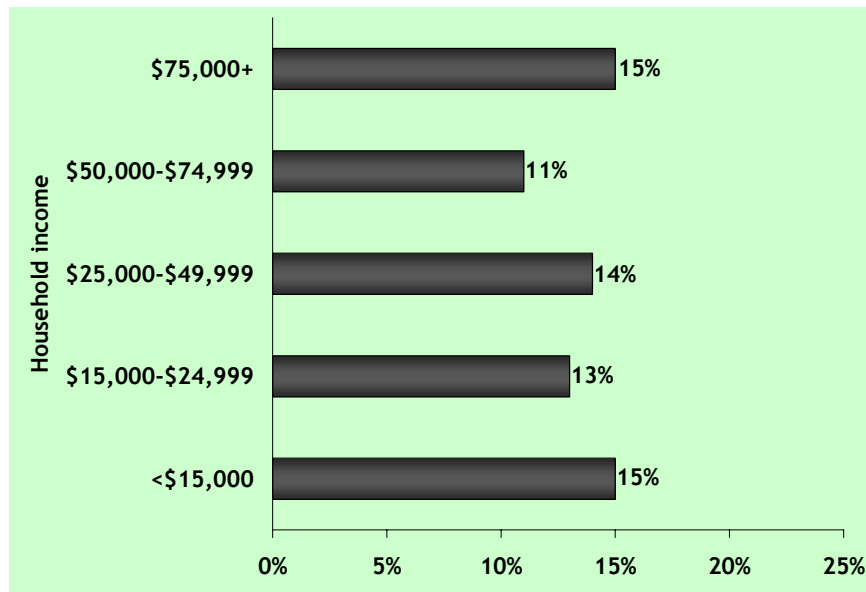
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## PREVALENCE OF CAREGIVING BY HOUSEHOLD INCOME

Adults of any household income in Hawaii have a similar likelihood of providing care or assistance to an elderly person.

**FIGURE 13: PREVALENCE OF CAREGIVING BY HOUSEHOLD INCOME**

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Based on Hawaii data.

Note: This figure represents the percent of respondents in each household income category who reported that they provided care or assistance to someone 60 years of age or older in the month prior to the study.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

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## **HAWAII CAREGIVERS ARE REMARKABLY SIMILAR TO THEIR NON CAREGIVING COUNTERPARTS IN THE STATE, IN TERMS OF AGE, ETHNICITY, EDUCATION, INCOME, HOUSEHOLD SIZE, HEALTH, AND OTHER CHARACTERISTICS.**

To get a clearer picture of Hawaii caregivers and their demographic, socioeconomic, and health characteristics, it is prudent to compare caregivers with non-caregivers. Comparing caregivers with non-caregivers allows answering frequently raised questions about whether caregivers are any different from non-caregivers, such as: Are caregivers older than non-caregivers? Do caregivers have different levels of income? Do they have worse or the same health status as the non-caregivers?

### **AGE**

The average age of Hawaii family caregivers caring for someone aged 60 years or older is 47 years old.<sup>21</sup> Twenty-five percent of Hawaii family caregivers regularly caring for someone 60 years or older are themselves ages 60 years or older.<sup>22</sup>

### **GENDER**

Fifty-seven percent of Hawaii family caregivers caring for someone aged 60 years or older are female.<sup>23</sup>

### **ETHNICITY**

The ethnic distribution of Hawaii caregivers is very similar to the ethnic distribution of Hawaii adults in general.<sup>24</sup>

## **THE CHARACTERISTICS OF HAWAII CAREGIVERS ARE VERY SIMILAR ACROSS THE FOUR COUNTIES.**

Hawaii caregivers are very similar to their non-caregiving counterparts, in terms of age, ethnicity, education, household income, health, and other characteristics. The same holds across the four counties.<sup>25,26</sup>

(See CAREGIVERS BY COUNTY section for county data.)

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<sup>21</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

<sup>22</sup> *Ibid.*

<sup>23</sup> *Ibid.*

<sup>24</sup> *Ibid.*

<sup>25</sup> Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

<sup>26</sup> Hawaii State Department of Health. *Hawaii Health Survey*. 2003.

**TABLE 4: DEMOGRAPHIC CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	9%	12%
25-34	14%	20%
35-44	22%	21%
45-54	19%	18%
55-64	18%	12%
65+	18%	16%
Total	100%	100%
Gender		
Male	43%	52%
Female	57%	48%
Total	100%	100%
Marital status		
Married/living w/ partner	58%	59%
Not married	42%	41%
Total	100%	100%
County		
Honolulu	75%	73%
Hawaii	11%	12%
Kauai	4%	5%
Maui	9%	10%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	21%	29%
Native Hawaiian	20%	15%
Chinese	6%	5%
Filipino	17%	15%
Japanese	24%	22%
Other	12%	14%
Total	100%	100%

Based on Hawaii data.

The Table compares demographic characteristics of Hawaii caregivers and non-caregivers.

For example, 43% of caregivers were male; 52% of non-caregivers were male. Among caregivers, 21% were Caucasian; among non-caregivers, 29% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health, *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 5: SOCIOECONOMIC CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	7%	8%
High school graduate	34%	32%
Some college/technical school	28%	29%
College graduate	31%	30%
Total	100%	100%
Household income		
Under \$10,000	5%	5%
\$10,000 to \$14,999	6%	5%
\$15,000 to \$19,999	5%	5%
\$20,000 to \$24,999	6%	8%
\$25,000 to \$34,999	13%	13%
\$35,000 to \$49,999	16%	17%
\$50,000 to \$74,999	11%	15%
\$75,000 and over	15%	15%
Don't know/not sure/refused	22%	18%
Total	100%	100%
Employment status		
Employed	65%	68%
Retired	21%	18%
Other	14%	14%
Total	100%	100%

Based on Hawaii data.

The Table compares socioeconomic characteristics of Hawaii caregivers and non-caregivers.

For example, 7% of caregivers had some high school or less; 8% of non-caregivers had some high school or less. Among caregivers, 65% were employed; among non-caregivers, 68% were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health, *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 6: HEALTH CHARACTERISTICS OF HAWAII CAREGIVERS COMPARED TO NON-CAREGIVERS**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	7%
General health status		
Excellent	17%	22%
Very good	31%	33%
Good	36%	34%
Fair	11%	9%
Poor	4%	2%
Total	100%	100%

Based on Hawaii data.

The Table compares health characteristics of Hawaii caregivers and non-caregivers.

For example, 8% of caregivers had no health insurance; 7% of non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

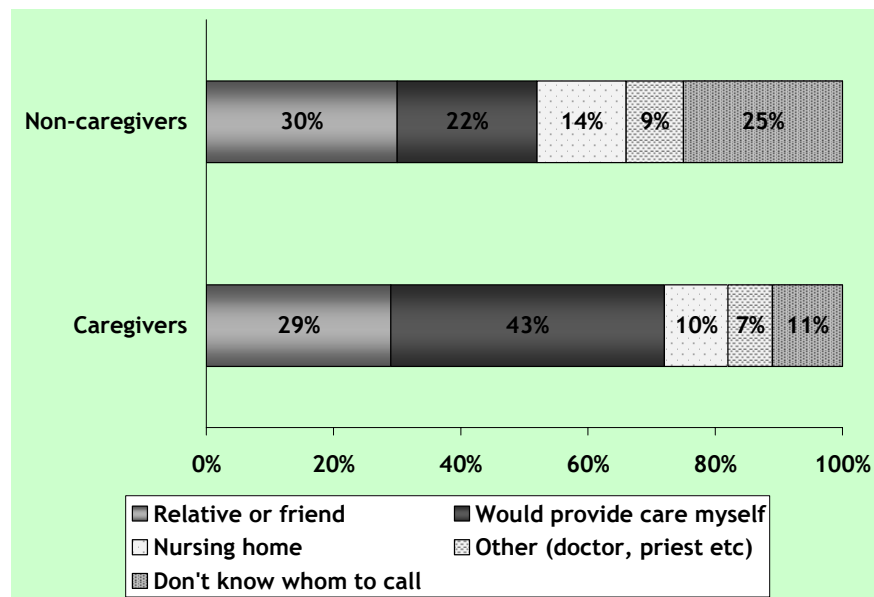
Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

## **MANY HAWAII ADULTS HAVE NO ONE TO CALL ON TO ASSIST WITH LONG-TERM CARE.**

Almost one-third of Hawaii adults, both caregivers and non-caregivers, say that they would call on relatives and friends to help them arrange for long-term care.

More caregivers than non-caregivers say that they would provide long-term care themselves rather than seek assistance.

One in four non-caregivers and approximately one in ten caregivers report that they do not know whom to call on for assistance with arranging long-term care.

**FIGURE 14: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"****TABLE 7: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?"**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	29%	30%
Would provide care myself	43%	22%
Nursing home or home health service	10%	14%
Doctor or nurse	3%	5%
Area Agency on Aging	2%	2%
Other	2%	2%
Don't know whom to call	11%	25%
Total	100%	100%

Based on Hawaii data.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

## CHARACTERISTICS OF CARE RECIPIENTS

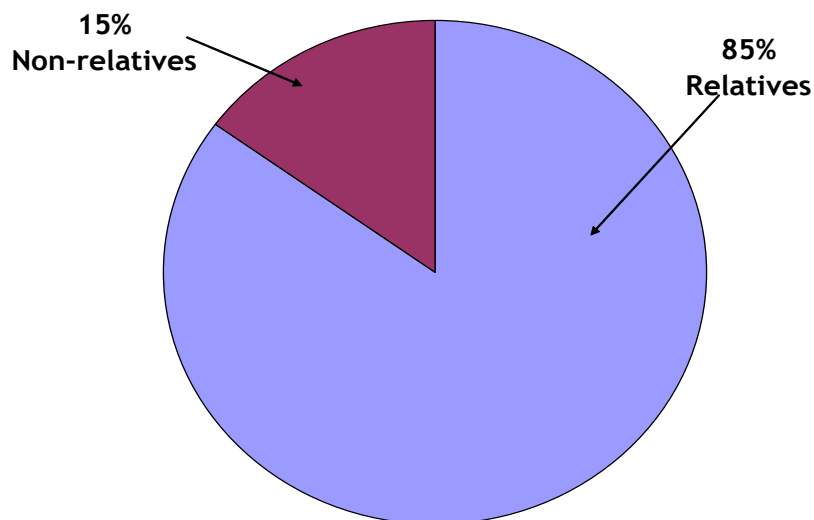
### NATIONAL DATA

Nationally, among persons ages 18 years old and older receiving personal care, the typical care recipient is female, widowed, and approximately 66 years of age. The majority of care recipients live in the same household or less than an hour away.<sup>27</sup>

### **MOST CARE RECIPIENTS ARE RELATIVES OF CAREGIVERS.**

Eighty-five percent of caregivers providing personal care to persons ages 50 years old and older say they care for relatives, most commonly for mothers (34%), grandmothers (11%), fathers (10%), mothers-in-law (8%), spouses (6%), siblings (4%), and daughters/sons (1%).<sup>28</sup>

**FIGURE 15: RELATIONSHIP BETWEEN CAREGIVER AND CARE RECIPIENT**



Based on national data.

Note: Data represents caregivers providing personal care to persons aged 50 years old and older.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>27</sup> Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>28</sup> *Ibid.*



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## AGE OF CARE RECIPIENTS

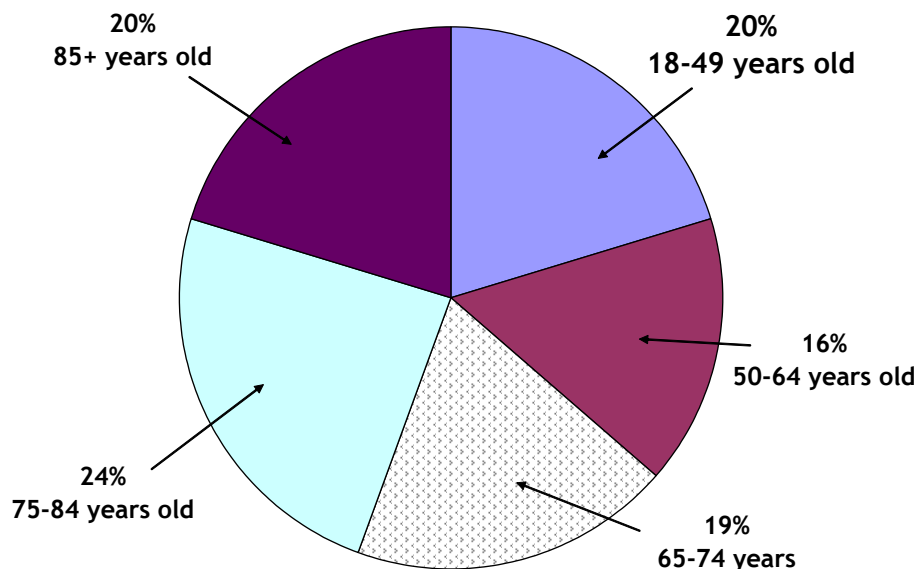
The majority (80%) of caregivers providing personal care say that they care for a person aged 50 years old or older.<sup>29</sup>

Among care recipients aged 50 years old or older receiving personal care, the average age of a care recipient is 75 years old.<sup>30</sup>

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**FIGURE 16: AGE DISTRIBUTION OF CARE RECIPIENTS**

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Based on national data.

Note: Data represents a study of caregivers providing personal care, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

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<sup>29</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

<sup>30</sup> *Ibid.*

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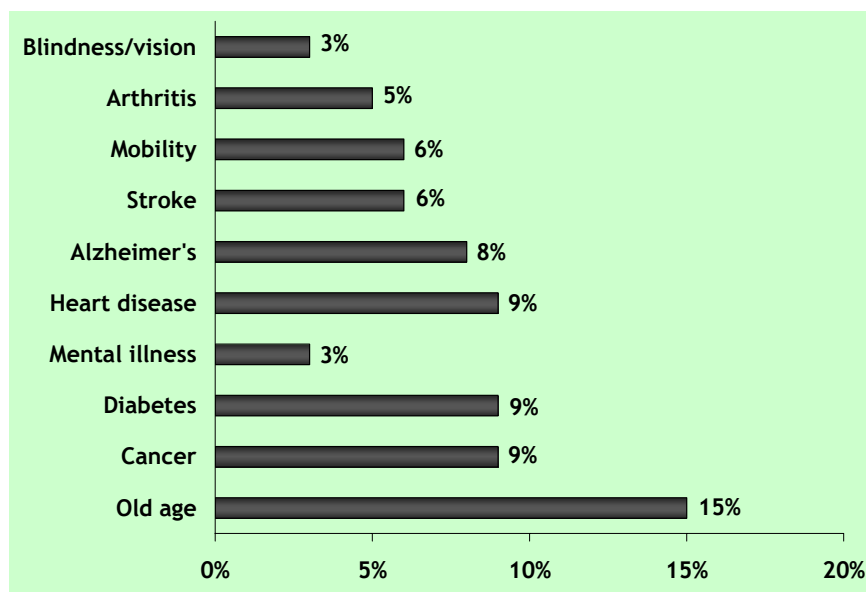
## HEALTH OF CARE RECIPIENTS

The primary illness or health problem of care recipients varies greatly, particularly by the age of the care recipient.

Among care recipients below the age of 50, the most commonly identified health problem is mental illness or emotional health. In contrast, among the care recipients aged 50 years old or older, the most commonly identified health problems are aging, being old, and the chronic conditions associated with aging.<sup>31</sup>

**FIGURE 17: MAIN PROBLEM OR ILLNESS OF CARE RECIPIENTS AS IDENTIFIED BY CAREGIVERS**

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Based on national data.

Note: Data represents a study of caregivers providing personal care to persons aged 50 years old and older, as presented in *Caregiving in the U.S. 2004*.

Source: National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

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<sup>31</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S. 2004*.

## HAWAII DATA

Reliable, population-based data on care recipients in the State of Hawaii is practically non-existent.

No population-based data, such as the characteristics of care recipients, their health status, the type or intensity of care they receive, or any other related data, is available regarding Hawaii's elderly who receive informal care and assistance from their relatives or friends.

This lack of data regarding Hawaii's elderly who receive informal care and assistance stems primarily from the fact that data on care recipients derive from national caregiving studies. As is frequently the case with other national studies, Hawaii receives extremely limited or no representation in these studies.

### PLACE OF RESIDENCE OF HAWAII CARE RECIPIENTS

One-fifth (20%) of Hawaii caregivers, who provide care to a person aged 60 years old or older, care for a person who lives in the same household. This pattern is similar in all four counties.

**TABLE 8: PERCENT OF CAREGIVERS LIVING IN THE SAME HOUSEHOLD WITH THE CARE RECIPIENT**

PERCENT OF CAREGIVERS WHO REPORTED THAT THE PERSON THEY CARE FOR LIVES IN SAME HOUSEHOLD	HONOLULU	HAWAII	KAUAI	MAUI	STATE
	20%	22%	22%	20%	20%

Based on Hawaii data.

Source: State Department of Health. *Hawaii Health Survey. 2003.*

## RELATIONSHIP BETWEEN HAWAII CAREGIVERS AND THEIR CARE RECIPIENTS

In Hawaii, among caregivers and care recipients living in the same household, the person most likely to provide care to an older person is a spouse or partner (29% of caregivers), a child (21%), or other relative (22%).

**TABLE 9: RELATION TO OLDER PERSON WHO RECEIVES CARE**

RELATION TO OLDER PERSON WHO RECEIVES CARE	% OF CAREGIVERS LIVING WITH CARE RECIPIENT				
	HONOLULU	HAWAII	KAUAI	MAUI	STATE
Spouse or partner	31%	29%	28%	22%	29%
Child	19%	27%	31%	27%	21%
Grandchild	10%	4%	6%	9%	9%
Other	40%	40%	35%	42%	41%
Total	100%	100%	100%	100%	100%

Based on Hawaii data.

Source: State Department of Health. *Hawaii Health Survey. 2003.*

## IMPACTS OF CAREGIVING

### ECONOMIC VALUE OF CAREGIVING

#### THE VALUE OF FAMILY CAREGIVING IS HIGH AND FAR SURPASSES WHAT IS SPENT ON HOME HEALTH CARE AND NURSING HOME CARE.

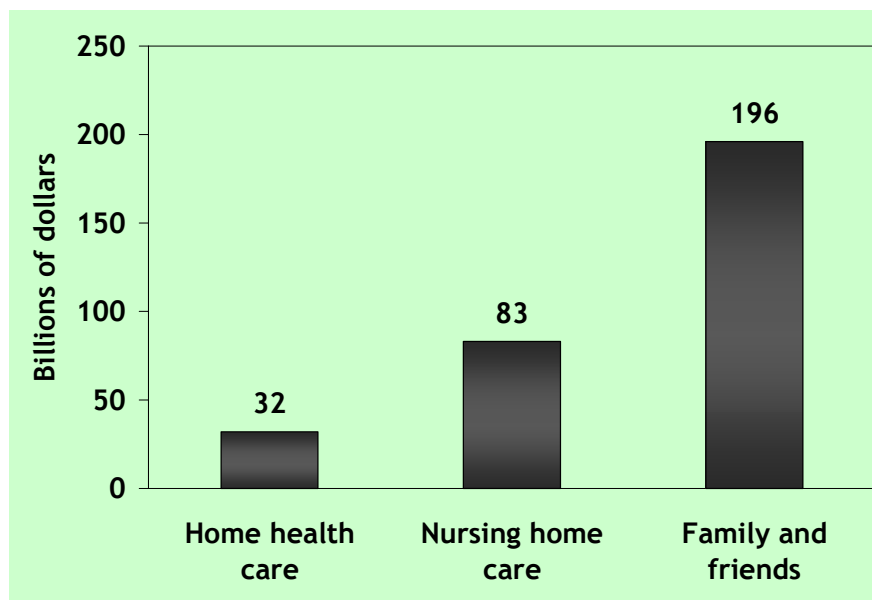
According to the *Economic Value of Informal Caregiving* study estimates, approximately 26 million family caregivers provided personal care to persons aged 15 years old and older, for a total of approximately 24 billion hours, resulting in an economic value of caregiving of \$196 billion a year nationally.<sup>32</sup>

<sup>32</sup> Arno, P., Levine, C., & Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

A more recent estimate valued family caregiving at \$257 billion a year nationally.<sup>33</sup> The economic value of care provided by family members and friends far surpasses what is spent on home health care and nursing home care.<sup>34</sup>

The same study estimated that approximately 115,000 family caregivers in Hawaii provided personal care to persons aged 15 years old and older, for a total of approximately 107 million hours, resulting in an estimated economic value of caregiving of approximately \$875 million per year.<sup>35</sup>

**FIGURE 18: ESTIMATED ECONOMIC VALUE OF FAMILY CAREGIVING, PER YEAR**



Based on national data.

Source: Arno, P., Levine, C., & Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>33</sup> Arno, P. *Economic Value of Informal Caregiving*. Presented at the American Association of Geriatric Psychiatry, February 24, 2002.

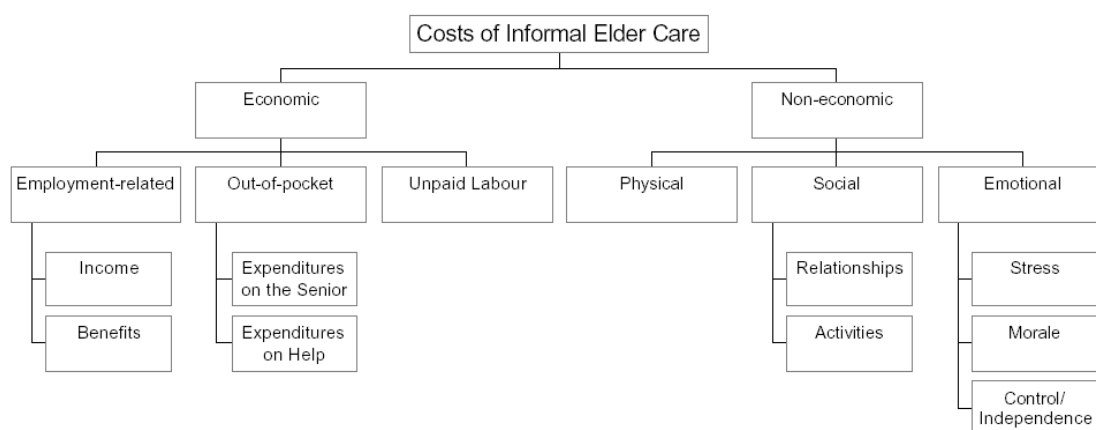
<sup>34</sup> Arno, P., Levine, C., & Memmott, M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>35</sup> *Ibid.*

## ECONOMIC AND NON-ECONOMIC COSTS OF CAREGIVING

It is increasingly recognized that the “free” care provided by caregivers to their family members and friends often comes at a high cost to caregivers themselves, in terms of impacts on their own health, well-being, employment, and other aspects of their lives, as can be seen in Figure 19 below.

**FIGURE 19: ECONOMIC AND NON-ECONOMIC COSTS OF INFORMAL ELDER CARE**



Source: Fast, J.E., & Keating, N.C. *Informal Caregivers in Canada: A Snapshot*. 2001.

## HEALTH IMPACT OF CAREGIVING

Elderly spouses, who are caregivers with a history of chronic illness themselves and who experience caregiving-related stress, have a 63% higher mortality rate than their non-caregiving peers.<sup>36</sup>

Research has shown that the stress of family caregiving for persons with dementia impacts a person's immune system for up to three years after their caregiving ends. Thus, this stress for caregivers increases their chances of developing a chronic illness themselves.<sup>37</sup>

<sup>36</sup> Schulz, R. & Beach, S.R. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, 282. 1999.

<sup>37</sup> Glaser, J.K. & Glaser, R. Chronic Stress and Age-related Increases in the Proinflammatory Cytokine IL-6. *Proceedings of the National Academy of Sciences*, June 30, 2003.

## COST OF CAREGIVING TO BUSINESS AND EMPLOYERS

There is a growing awareness that caring for older relatives is not just a family matter, but is something that exacts a cost on businesses and employers. Several studies have documented costs of caregiving to businesses, particularly in terms of the:

- Replacement costs for employees who quit due to their caregiving responsibilities
- Absenteeism costs
- Costs due to workday interruptions
- Costs due to eldercare crises
- Costs associated with supervising employed caregivers
- Costs associated with the detrimental impact of caregiving responsibilities on caregivers' health.

According to the 1997 National Alliance for Caregiving/MetLife study of employer costs for working caregivers:<sup>38</sup>

- The majority of caregivers are employed;
- Many caregivers quit or change their jobs due to their caregiving Responsibilities; and
- It is estimated that U.S. businesses lose between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older.

### THE MAJORITY OF CAREGIVERS ARE EMPLOYED.

One in four U.S. households, or estimated 22,411,200 households, are involved in caregiving. The majority of these of these caregivers are employed. This data translates into 14.4 million full and part-time employed caregivers who are balancing work with their caregiving roles.

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<sup>38</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers*. Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.

Note: This study focused on caregivers who were employed full-time and who were providing personal care. These caregivers were, on average, providing assistance with 2 or more Activities of Daily Living (bathing, feeding, toileting, transferring from chair or bed, or walking), and 4 or more Instrumental Activities of Daily Living (financial management, transportation, help with medications, shopping, preparing meals, etc.) for an average of at least 9 hours of care each week. This study based its estimates of the costs of caregiving to businesses upon the estimated 5.7 million of such caregivers.

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## **MANY CAREGIVERS QUIT OR CHANGE THEIR JOBS DUE TO THEIR CAREGIVING RESPONSIBILITIES.**

According to the 1997 MetLife Study of Employer Costs for Working Caregivers (Metlife Study), one-tenth of caregivers permanently left the workforce; of these caregivers, 4% took early retirement and another 6% left work without any retirement benefits. Another 11% of caregivers reported that they took a leave of absence; 7% of caregivers changed from full-time work to part-time work or took a less demanding job.

## **IT IS ESTIMATED THAT U.S. BUSINESSES LOSE BETWEEN \$11 BILLION AND \$29 BILLION EACH YEAR DUE TO EMPLOYEES' NEED TO CARE FOR LOVED ONES 50 YEARS OF AGE AND OLDER.**

### **REPLACEMENT COSTS FOR EMPLOYEES WHO QUIT IN ANY YEAR**

Seventeen percent of caregivers who were employed when they began providing personal care reported in the Metlife study that they quit their jobs or took early retirement because of their caregiving responsibilities.

Replacement costs, including recruiting, relocation, training, the temporary inefficiency of new hires and vacant positions, have been estimated to cost employers as much as \$5 billion annually.<sup>39</sup>

### **WORK HOURS LOST DUE TO ABSENTEEISM**

One in ten employed caregivers providing personal care were absent a minimum of three or more days in a six months period previous to the Metlife study (or a minimum of 6 days per year) due to caregiving responsibilities.

Fifty-nine percent of caregivers providing personal care who are employed reported that they had to adjust their work schedules, including changing their lunch hour, leaving work early, and so forth. On average, these caregivers lost a minimum of 1 hour per week for an aggregate annual loss of 50 hours per caregiver that could not be made up.

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<sup>39</sup> National Alliance for Caregiving/MetLife. *The MetLife Study of Employer Costs for Working Caregivers*. Based on data from Family Caregiving in the U.S.: Findings from a National Survey. 1997.



## **WORK HOURS LOST DUE TO WORKDAY INTERRUPTIONS**

Many caregivers reported in the Metlife study that they experienced interruptions during the day due to the performance of caregiving tasks, such as making phone calls to the care recipient or to service providers, receiving phone calls, and so forth. The total lost work time due to these interruptions were estimated at 1 hour per week for 50 weeks for those employed caregivers providing personal care.

## **WORK DAYS LOST DUE TO ELDERCARE CRISES**

Sixty percent of employed caregivers reported experiencing an eldercare crisis in the six months prior to the Metlife study (e.g., the person receiving care was hospitalized.) The Metlife study estimated the time lost to additional phone calls, loss of concentration and partial absenteeism in dealing with such crises at 3 days per year.

# **KEY TRENDS AFFECTING CAREGIVING**

## **NATIONAL TRENDS**

### **THE U.S. POPULATION IS AGING.**

The population aged 65 years old and older is expected to double, from 35 million persons in 2000 (representing 12% of the population) to an estimated 70 million person by 2030 (representing 20% of the population).<sup>40</sup>

The very old, aged 85 years old or older—those most in need of long-term care—are the fastest growing segment of the U.S. population. This age group is expected to grow from approximately 4 million persons in 2000 to an estimated 9 million persons in 2030.

<sup>40</sup> U.S. Administration on Aging. *A Profile of Older Americans: 2003*.

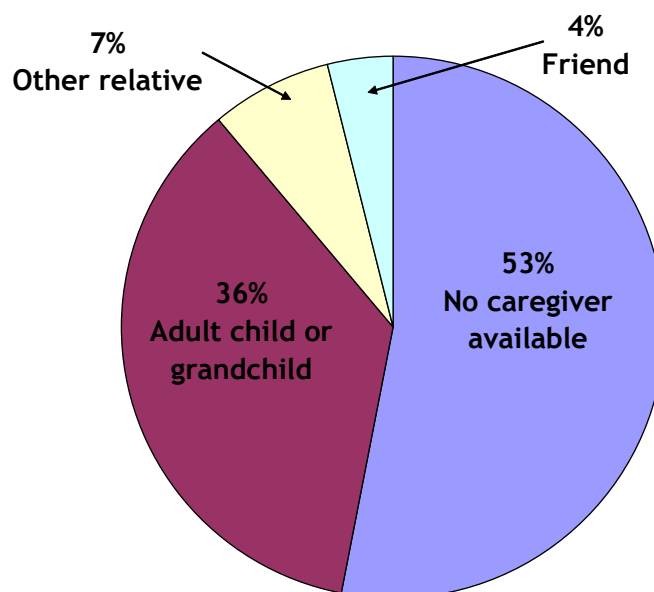
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## MILLIONS OF ELDERLY ARE PROJECTED TO NEED CARE.

The majority of people who do not have caregivers do not expect to have a caregiver in the future. Among older adults aged 70 years old and older who were not receiving help at the time of the study, more than half (53%) reported that they did not expect to have a caregiver available in the future; whereas approximately one-third (36%) reported their belief that their child or grandchild would be available to provide them needed care.<sup>41</sup>

**FIGURE 20: AVAILABILITY OF CAREGIVERS IN THE FUTURE AS PERCEIVED BY PERSONS AGED 70 YEARS OLD AND OLDER WHO DO NOT CURRENTLY RECEIVE HELP**

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Based on national data.

Source: National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons aged 70 years old and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

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<sup>41</sup> National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

## MANY ELDERLY WITH ACTIVITY LIMITATIONS EXPECT TO MOVE. EXPECTATIONS ABOUT CARE IN THE FUTURE VARY BY GENDER.

Approximately one in four persons ages 70 and older with activity limitations report that they are likely to move in the next five years.<sup>42</sup>

Of those who expect to move in the next five years, a higher proportion of men than women expect to buy or rent a residence. Women are more likely to expect that they will live in a setting where care may be available, such as a retirement home/community, another person's home, or nursing home.<sup>43</sup>

**TABLE 10: WHERE DO PEOPLE AGE 70+ WITH ACTIVITY LIMITATIONS WHO EXPECT TO MOVE THINK THEY WILL LIVE IN THE NEXT FIVE YEARS?**

	% OF MEN WHO EXPECT TO MOVE	% OF WOMEN WHO EXPECT TO MOVE
Would buy or rent	64%	38%
Another person's home	10%	17%
Nursing home	7%	15%
Retirement home/community	19%	30%
Total	100%	100%

Based on national data.

Source: National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

<sup>42</sup> National Academy on an Aging Society analysis of data from the 1993 study of Assets and Health Dynamics Among the Oldest Old (AHEAD) or persons age 70 and older. Reported in: National Academy on an Aging Society. *Caregiving: Helping the Elderly with Activity Limitations*. Number 7, May 2000.

<sup>43</sup> *Ibid.*

## HAWAII TRENDS

### PERCENT AND NUMBER OF HAWAII'S OLDER ADULT POPULATION CONTINUES TO GROW

Hawaii's older adult population (60 years of age or older) continues to grow in number and as a percent of the State's total population. In 1980, there were 113,944 adults aged 60 years old or older, which represented 12% of the total population. By 2000, there were 207,001 individuals aged 60 years old or older, which represented 17% of State's total population.<sup>44</sup> With the aging of the baby boomer generation, it is projected that, by 2030, one in four persons will be aged 60 years old or older.<sup>45</sup>

Between 1980 and 2000, Hawaii's older adult population increased by 82%, while the State's total population increased by 26%.<sup>46</sup>

The population aged 85 years old or older increased even more dramatically. While the total population increased by 26% from 1980 to 2000, the population aged 85 years old or older increased by 216%.<sup>47</sup>

### HAWAII OLDER ADULT POPULATION IS INCREASING FASTER THAN IN THE REST OF THE U.S.

The older adult population in Hawaii is increasing considerably faster than in the rest of the country. While Hawaii's older adult population increased by 19% between 1990 and 2000, the U.S. as a whole saw a 9% increase in individuals aged 60 years old or older over the same time period. Between 1990 and 2000, Hawaii's population aged 85 years old or older grew 69%, while the same population group grew 38% nationally.<sup>48</sup>

<sup>44</sup> U.S. Census Bureau. April 1, 1980 and 2000 estimates.

<sup>45</sup> Hawaii Department of Business, Economic Development and Tourism. *Population and Economic Projections for the State of Hawaii to 2030*. August 2004.

<sup>46</sup> U.S. Census Bureau. April 1, 1980 and 2000 estimates.

<sup>47</sup> *Ibid.*

<sup>48</sup> U.S. Census Bureau. April 1, 1990 and 2000 estimates.

## LIFE EXPECTANCY CONTINUES TO INCREASE.

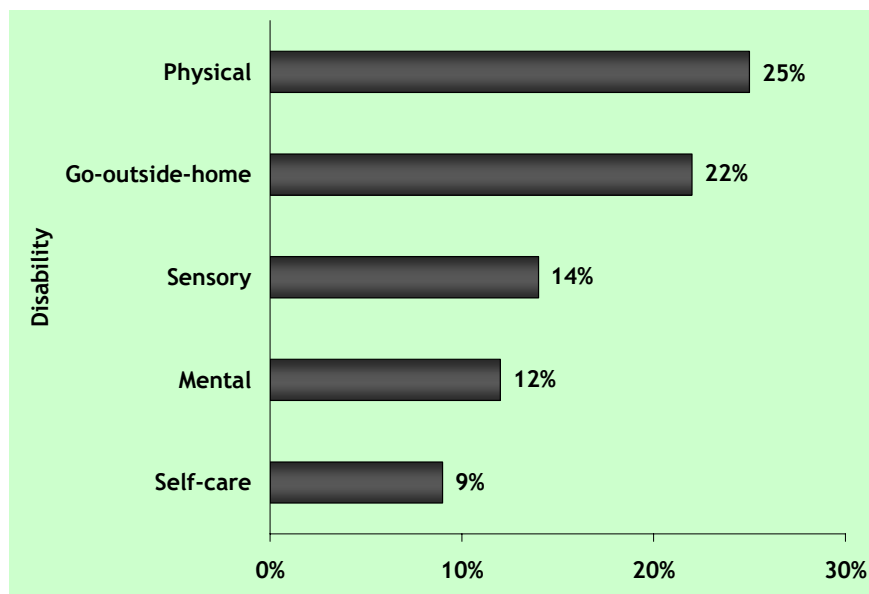
Life expectancy continues to increase, with Hawaii enjoying one of the highest life expectancies in the nation.<sup>49</sup>

Even though Hawaii residents enjoy high life expectancy, there are differences in life expectancy across the race/ethnicity groups in the State with Native Hawaiians having a lower life expectancy than Chinese and Japanese.<sup>50</sup>

## MANY OLDER ADULTS HAVE AT LEAST ONE DISABILITY.

Approximately four out of ten persons in Hawaii aged 65 years old or older have a disability, defined as having one or more of the following disabilities: sensory, physical, mental, self-care, and/or go-outside-the-home-alone. Over half of these persons have at least two of these disabilities.<sup>51</sup>

**FIGURE 21: PERCENT OF ADULTS AGED 65 YEARS OLD OR OLDER WHO HAVE SPECIFIC DISABILITIES**



Based on Hawaii data.

Source: U.S. Census Bureau. *Census 2000*.

<sup>49</sup> Centers for Disease Control and Prevention. *National Vital Statistics Reports*. 2003; and Hawaii Department of Business, Economic Development and Tourism. *The State of Hawaii Data Book*. 2003.

<sup>50</sup> Hawaii Health Information Corporation. *Health Trends in Hawaii*.

<sup>51</sup> U.S. Census Bureau. *Census 2000*.

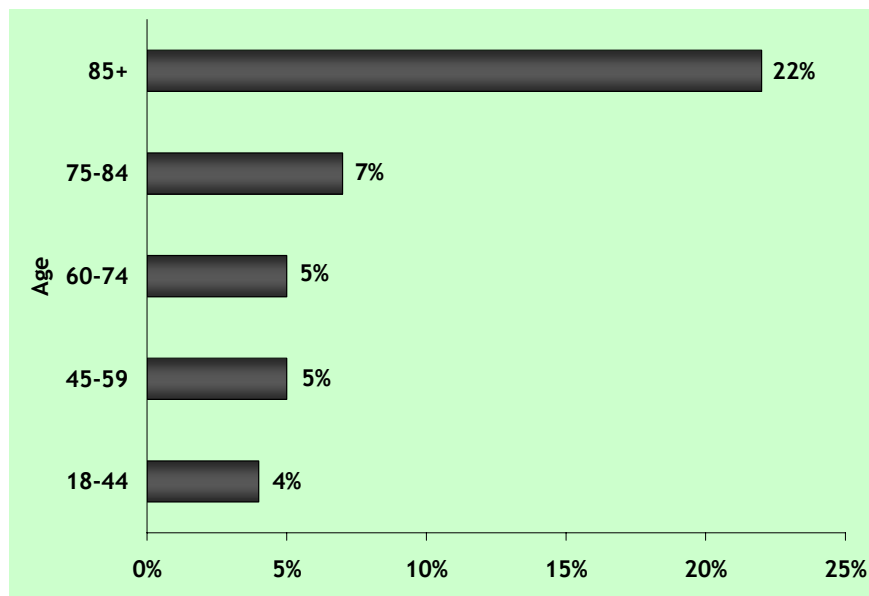
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## NEED FOR ASSISTANCE WITH PERSONAL CARE INCREASES WITH AGE.

As may be expected, the need for personal care increases with age. Approximately 5%, 7% and 22% of adults in the 60-74, 75-84 and 85+ age groups respectively, report that they need help with personal care.<sup>52</sup>

**FIGURE 22: PERCENT OF ADULTS WHO NEED HELP WITH PERSONAL CARE**

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Based on Hawaii data.

Source: Hawaii Department of Health. *Hawaii Health Survey. 2000.*

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<sup>52</sup> Hawaii Department of Health. *Hawaii Health Survey. 2000.*

## FAMILY CAREGIVERS BY COUNTY

**TABLE 11: PREVALENCE OF CAREGIVING BY CHARACTERISTICS AND COUNTY**

	HAWAII COUNTY	HONOLULU COUNTY	KAUAI COUNTY	MAUI/KALAWAO COUNTY
Age				
18-24	16%	9%	18%	15%
25-34	10%	10%	8%	7%
35-44	12%	16%	13%	13%
45-54	17%	16%	13%	9%
55-64	17%	20%	20%	19%
65+	11%	15%	11%	17%
Gender				
Male	13%	12%	12%	12%
Female	14%	17%	15%	13%
Marital status				
Married/living w/ partner	13%	14%	12%	14%
Not married	14%	15%	16%	11%
Ethnicity (self-identified)				
Caucasian	11%	11%	14%	11%
Native Hawaiian	18%	19%	15%	14%
Filipino	13%	16%	13%	15%
Japanese	16%	15%	11%	13%
Other	10%	13%	14%	14%
Employment status				
Employed	14%	14%	14%	11%
Unemployed	22%	20%	--	--
Student/Homemaker	11%	11%	14%	21%
Retired	11%	17%	11%	17%
Household income				
< \$15,000	13%	17%	8%	11%
\$15K to \$24,999	17%	12%	14%	13%
\$25K to \$49,999	10%	15%	12%	11%
\$50K to \$74,999	15%	10%	16%	16%
\$75,000 and over	17%	15%	18%	8%

-- Cell size too small to form a meaningful estimate.

For example, 13% of adult males in Hawaii County reported providing regular care to someone age 60+; in the remaining counties this figure was 12%. 11% of employed adults in Maui/Kalawao County reported providing regular care to someone age 60+; in the remaining counties this figure was 14%.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 12: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HAWAII COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	12%	10%
25-34	14%	18%
35-44	19%	22%
45-54	23%	18%
55-64	16%	13%
65+	16%	20%
Total	100%	100%
Gender		
Male	47%	50%
Female	53%	50%
Total	100%	100%
Marital status		
Married/living w/ partner	57%	60%
Not married	43%	40%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	31%	36%
Native Hawaiian	31%	22%
Chinese	0%	2%
Filipino	8%	9%
Japanese	22%	19%
Other	8%	12%
Total	100%	100%

The Table compares demographic characteristics of Hawaii County caregivers and non-caregivers.

For example, 47% of Hawaii County caregivers were male; 50% of Hawaii County non-caregivers were male. Among Hawaii County caregivers, 31% were Caucasian; among Hawaii County non-caregivers, 36% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*



**TABLE 13: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HAWAII COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	9%	7%
High school graduate	36%	36%
Some college/technical school	30%	29%
College graduate	26%	27%
Total	100%	100%
Household income		
Under \$10,000	8%	7%
\$10,000 to \$14,999	6%	7%
\$15,000 to \$19,999	11%	6%
\$20,000 to \$24,999	8%	8%
\$25,000 to \$34,999	10%	15%
\$35,000 to \$49,999	13%	16%
\$50,000 to \$74,999	14%	13%
\$75,000 and over	13%	10%
Don't know/not sure/refused	17%	17%
Total	100%	100%
Employment status		
Employed	68%	64%
Retired	18%	20%
Other	14%	16%
Total	100%	100%

The Table compares socioeconomic characteristics of Hawaii County caregivers and non-caregivers.

For example, 68% of Hawaii County caregivers were employed; 64% of Hawaii County non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 14: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HONOLULU COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	8%	13%
25-34	14%	20%
35-44	22%	20%
45-54	20%	18%
55-64	19%	12%
65+	17%	16%
Total	100%	100%
Gender		
Male	41%	52%
Female	59%	48%
Total	100%	100%
Marital status		
Married/living w/ partner	59%	60%
Not married	41%	40%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	18%	27%
Native Hawaiian	19%	14%
Chinese	7%	6%
Filipino	18%	15%
Japanese	26%	24%
Other	12%	14%
Total	100%	100%

The Table compares demographic characteristics of Honolulu County caregivers and non-caregivers.

For example, 41% of Honolulu County caregivers were male; 52% of Honolulu County non-caregivers were male. Among Honolulu County caregivers, 18% were Caucasian; among Honolulu County non-caregivers, 27% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 15: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HONOLULU COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	6%	8%
High school graduate	34%	31%
Some college/technical school	27%	28%
College graduate	33%	32%
Total	100%	100%
Household income		
Under \$10,000	4%	4%
\$10,000 to \$14,999	6%	5%
\$15,000 to \$19,999	4%	4%
\$20,000 to \$24,999	5%	7%
\$25,000 to \$34,999	14%	12%
\$35,000 to \$49,999	17%	17%
\$50,000 to \$74,999	10%	15%
\$75,000 and over	17%	16%
Don't know/not sure/refused	22%	19%
Total	100%	100%
Employment status		
Employed	65%	68%
Retired	22%	17%
Other	13%	15%
Total	100%	100%

The Table compares socioeconomic characteristics of Honolulu County caregivers and non-caregivers.

For example, 65% of Honolulu County caregivers were employed; 68% of Honolulu County non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 16: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****KAUAI COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	14%	10%
25-34	11%	19%
35-44	22%	22%
45-54	18%	17%
55-64	20%	12%
65+	16%	20%
Total	100%	100%
Gender		
Male	43%	51%
Female	57%	49%
Total	100%	100%
Marital status		
Married/living w/ partner	54%	59%
Not married	46%	41%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	27%	33%
Native Hawaiian	17%	15%
Chinese	2%	1%
Filipino	20%	20%
Japanese	13%	13%
Other	21%	18%
Total	100%	100%

The Table compares demographic characteristics of Kauai County caregivers and non-caregivers.

For example, 43% of Kauai County caregivers were male; 51% of Kauai County non-caregivers were male. Among Kauai County caregivers, 27% were Caucasian; among Kauai County non-caregivers, 33% were Caucasian.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 17: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****KAUAI COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	4%	13%
High school graduate	32%	32%
Some college/technical school	32%	28%
College graduate	32%	28%
Total	100%	100%
Household income		
Under \$10,000	2%	9%
\$10,000 to \$14,999	8%	10%
\$15,000 to \$19,999	5%	5%
\$20,000 to \$24,999	9%	8%
\$25,000 to \$34,999	8%	13%
\$35,000 to \$49,999	17%	16%
\$50,000 to \$74,999	15%	12%
\$75,000 and over	14%	10%
Don't know/not sure/refused	23%	17%
Total	100%	100%
Employment status		
Employed	71%	68%
Retired	16%	21%
Other	13%	11%
Total	100%	100%

The Table compares socioeconomic characteristics of Kauai County caregivers and non-caregivers.

For example, 71% of Kauai County caregivers were employed; 68% of Kauai County non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 18: DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****MAUI/KALAWAO COUNTY**

DEMOGRAPHIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Age		
18-24	12%	10%
25-34	11%	20%
35-44	23%	23%
45-54	12%	19%
55-64	19%	11%
65+	23%	16%
Total	100%	100%
Gender		
Male	49%	51%
Female	51%	49%
Total	100%	100%
Marital status		
Married/living w/ partner	64%	57%
Not married	36%	43%
Total	100%	100%
Ethnicity (self-identified)		
Caucasian	33%	38%
Native Hawaiian	19%	16%
Chinese	1%	2%
Filipino	21%	17%
Japanese	16%	16%
Other	10%	11%
Total	100%	100%

The Table compares demographic characteristics of Maui\* County caregivers and non-caregivers.

For example, 49% of Maui\* County caregivers were male; 51% of Maui\* County non-caregivers were male. Among Maui\* County caregivers, 33% were Caucasian; among Maui\* County non-caregivers, 38% were Caucasian.

The percentages may not sum to 100% due to rounding.

\* Maui/Kalawao County.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 19: SOCIOECONOMIC CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****MAUI/KALAWAO COUNTY**

SOCIOECONOMIC CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Education		
Some high school or less	8%	10%
High school graduate	38%	33%
Some college/technical school	32%	33%
College graduate	22%	24%
Total	100%	100%
Household income		
Under \$10,000	5%	6%
\$10,000 to \$14,999	4%	5%
\$15,000 to \$19,999	3%	6%
\$20,000 to \$24,999	11%	8%
\$25,000 to \$34,999	14%	14%
\$35,000 to \$49,999	13%	20%
\$50,000 to \$74,999	19%	14%
\$75,000 and over	7%	11%
Don't know/not sure/refused	24%	16%
Total	100%	100%
Employment status		
Employed	62%	72%
Retired	25%	18%
Other	13%	10%
Total	100%	100%

The Table compares socioeconomic characteristics of Maui\* County caregivers and non-caregivers.

For example, 62% of Maui\* County caregivers were employed; 72% of Maui\* County non-caregivers were employed.

The percentages may not sum to 100% due to rounding.

\* Maui/Kalawao County.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System. 2000.*

**TABLE 20: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HAWAII COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	9%
General health status		
Excellent	19%	21%
Very good	26%	33%
Good	44%	31%
Fair	10%	11%
Poor	2%	3%
Total	100%	100%

**TABLE 21: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****HONOLULU COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	8%	6%
General health status		
Excellent	17%	22%
Very good	32%	33%
Good	35%	34%
Fair	11%	9%
Poor	5%	2%
Total	100%	100%

The Tables compare health characteristics of caregivers and non-caregivers.

For example, 19% of Hawaii County caregivers rated their general health as Excellent; 21% of Hawaii County non-caregivers rated their general health as Excellent.

For example, 8% of Honolulu County caregivers had no health insurance; 6% of Honolulu County non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.



**TABLE 22: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****KAUAI COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	7%	11%
General health status		
Excellent	19%	18%
Very good	32%	32%
Good	39%	38%
Fair	10%	9%
Poor	0%	2%
Total	100%	100%

**TABLE 23: HEALTH CHARACTERISTICS OF CAREGIVERS COMPARED TO NON-CAREGIVERS;****MAUI/KALAWAO COUNTY**

HEALTH CHARACTERISTICS	% OF CAREGIVERS	% OF NON-CAREGIVERS
Has no health insurance	12%	8%
General health status		
Excellent	16%	24%
Very good	29%	34%
Good	36%	30%
Fair	17%	9%
Poor	2%	3%
Total	100%	100%

The Tables compare health characteristics of caregivers and non-caregivers.

For example, 19% of Kauai County caregivers rated their general health as Excellent; 18% of Kauai County non-caregivers rated their general health as Excellent.

For example, 12% of Maui/Kalawao County caregivers had no health insurance; 8% of Maui/Kalawao County non-caregivers had no health insurance.

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 24: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?";****HAWAII COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	29%	25%
Would provide care myself	43%	25%
Nursing home or home health service	11%	14%
Doctor or nurse	5%	5%
Area Agency on Aging	2%	2%
Other	2%	4%
Don't know whom to call	8%	25%
Total	100%	100%

**TABLE 25: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?";****HONOLULU COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	30%	31%
Would provide care myself	44%	22%
Nursing home or home health service	8%	13%
Doctor or nurse	3%	4%
Area Agency on Aging	2%	2%
Other	2%	3%
Don't know whom to call	11%	25%
Total	100%	100%

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

**TABLE 26: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?";****KAUAI COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	14%	25%
Would provide care myself	42%	19%
Nursing home or home health service	11%	11%
Doctor or nurse	2%	7%
Area Agency on Aging	9%	3%
Other	2%	3%
Don't know whom to call	20%	32%
Total	100%	100%

**TABLE 27: "WHO WOULD YOU CALL TO ARRANGE FOR LONG-TERM CARE?";****MAUI/KALAWAO COUNTY**

	% OF CAREGIVERS	% OF NON-CAREGIVERS
Relative or friend	26%	24%
Would provide care myself	36%	20%
Nursing home or home health service	22%	16%
Doctor or nurse	3%	4%
Area Agency on Aging	1%	3%
Other	5%	4%
Don't know whom to call	7%	29%
Total	100%	100%

The percentages may not sum to 100% due to rounding.

Source: Hawaii State Department of Health. *Behavioral Risk Factor Surveillance System*. 2000.

## DATA ISSUES

### INTERPRETING NATIONAL AND HAWAII DATA ON CAREGIVERS

Data on caregivers and the persons for whom they care come from a wide variety of sources and studies. These various studies and sources:

- Follow different methodologies
- Focus on different aspects of caregiving
- Ask questions on different topics and/or on similar topics but use differently-worded questions, and
- Most importantly, often use varying definitions of a caregiver and a care recipient.

As a result, certain statistics often vary widely from source to source. Thus, national statistics derived from the most commonly referenced caregiver studies—all of which are conducted by highly reputable agencies that follow rigorous methodologies—produce estimates of the number of caregivers ranging from as low as 5.9 million caregivers to as high as 52 million caregivers in the U.S. These variances illustrate the need to exert great care in interpreting those statistics and placing them in the proper context.

This same caution should be used when interpreting Hawaii data on caregivers as well. Even though the estimates of the number of caregivers in the State derive from the same survey question, these caregiver surveys, the BRFSS and HHS, are conducted using different sampling methodologies.

## CAREGIVERS GO THROUGH STAGES OF CAREGIVING.

Another issue closely related to the issue of defining the term “caregiver” is the issue related to defining the stages of caregiving. To capture the diversity of the “caregiver” phenomenon, several focus group participants and the EOA staff pointed to the nationally recognized conceptual framework of stages of caregiving (the so-called Montgomery stages of caregiving framework<sup>53,54</sup>).

The Stages of Caregiving framework is based on the premise that caregiving is a dynamic process which unfolds over time. This framework outlines the following key stages in the “caregiver career” that mark significant shifts in caregiving experiences (see Appendix for details):

- I. Performing caregiving tasks
- II. Self-definition as a caregiver
- III. Performing personal care
- IV. Seeking assistance and formal service use
- V. Institutionalization
- VI. Termination of the caregiving role

Acknowledging several distinct stages of caregiving, as conceptualized in the above-described framework, has major implications for planning and delivery of caregiver support services, and, thus, data collection and interpretation:

- Caregivers may need a range of caregiver support services. For example, certain caregivers simply need information; certain caregivers may need emotional support; certain other caregivers may need assistance with direct care tasks and respite.
- Caregivers may need different types of support, depending upon the “stage of caregiving.” For example, respite is not really needed in the early stages of caregiving, but may be desperately needed in later stages.
- Caregiver support needs are likely to be different for different cultural groups, as different cultures experience the stages of caregiving differently and have different community and family resources to draw on.
- If services are not available at certain stages of caregiving, caregivers may prematurely consider nursing home placement.
- Without proper services and support, many caregivers disrupt their employment, change jobs, or quit them altogether, often with major consequences for the caregiver’s retirement and financial resources.

<sup>53</sup> Montgomery, R.J.V., & Hatch L. *The Feasibility of Volunteers and Families Forming a Partnership for Caregiving*. In Brubaker T (Ed.), *Family and Long-term Care* (pp. 143-161). 1997. Beverly Hills, CA: Sage Publications.

<sup>54</sup> Pearlin, L.I. The Careers of Caregivers. *The Gerontologist*, 32:647. 1992.

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**MANY CAREGIVERS DO NOT SELF-IDENTIFY THEMSELVES AS CAREGIVERS.**

High prevalence of caregivers who do not self-identify themselves as such has major implications for program and service planning and delivery, as well as data collection and interpretation:

- High numbers of caregivers that do not self-identify themselves as such imply that estimates of the number of people who are caregivers are likely to be underestimated.
- Self-identifying as a caregiver has important implications: according to national studies, family caregivers who acknowledge their role are more proactive in reaching out for resources.<sup>55</sup>
- Not “self-identifying” may foster relative invisibility of caregiver issues at the state level.
- Not “self-identifying” may impede with caregivers’ empowerment in the communities and limit opportunities for their recognition in the state.

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<sup>55</sup> National Family Caregivers Association. *Survey of Self-Identified Family Caregivers, 2001*.

## SOURCES OF DATA ON FAMILY CAREGIVERS

### NATIONAL SOURCES

National data on caregivers and the care recipients to whom they provide care derive from two main types of data sources:

- Special studies on caregiving sponsored by various government and private agencies
- Behavioral Risk Factor Surveillance System (BRFSS) conducted by the Centers of Disease Control and Prevention (CDC) in partnership with all the states.

Most of the available data on caregivers and care recipients derive from **special studies** that were sponsored and conducted by various government and private agencies to specifically obtain information on caregiving related issues. These studies include:

- Caregiving in the U.S.<sup>56</sup>
- Caregiver Survey, by the National Family Caregivers Association (2000)
- Long-Term Care from the Caregiver's Perspective<sup>57</sup>
- The Characteristics of Long-Term Care Users<sup>58,59</sup>
- Family Caregiving in the U.S.: Findings from a National Survey<sup>60,61,62,63,64,65</sup>
- The Economic Value of Informal Caregiving<sup>66,67</sup>
- Informal Caregiving: Compassion in Action, Parts I and II<sup>68,69,70</sup>

<sup>56</sup> National Alliance for Caregiving & AARP. *Caregiving in the U.S.* 2004.

<sup>57</sup> The Henry J. Kaiser Family Foundation, Harvard School of Public Health, United Hospital Fund of New York, Visiting Nurse Service of New York. *The Wide Circle of Caregiving. Key Findings from a National Survey: Long-Term Care from the Caregiver's Perspective.* 2002.

<sup>58</sup> Spector, W.D., et al. *The Characteristics of Long-Term Care Users* (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD. 2000.

<sup>59</sup> Health and Human Services. *Informal Caregiving: Compassion in Action.* Department of Health and Human Services, Washington, DC. 1998.

<sup>60</sup> National Alliance for Caregiving & AARP. *Family Caregiving in the U.S.: Findings From a National Survey, National Alliance for Caregiving, Bethesda, MD and AARP, Washington, DC.* 1997.

<sup>61</sup> MetLife Mature Market Group & National Alliance for Caregiving. *The MetLife Study of Employer Costs for Working Caregivers.* MetLife Mature Market Group, Westport, CT and National Alliance for Caregiving, Bethesda, MD. 1997.

<sup>62</sup> Arno, P.S., Levine, C., & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>63</sup> Alzheimer's Association & National Alliance for Caregiving. *Who Cares: Families Caring for Persons with Alzheimer's Disease.* Alzheimer's Association, Washington, DC & National Alliance for Caregiving, Bethesda, MD. 1999.

<sup>64</sup> Wagner, D.L. *Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997.* National Alliance for Caregiving, Bethesda, MD. 1997.

<sup>65</sup> Ory, M.G., et al. Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. *The Gerontologist*, 39:177-185. 1999.

<sup>66</sup> Arno, P.S., Levine, C. & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>67</sup> Health and Human Services. *Informal Caregiving: Compassion in Action.* Department of Health and Human Services, Washington, DC. 1998.

<sup>68</sup> Health and Human Services. *Informal Caregiving: Compassion in Action.* Department of Health and Human Services, Washington, DC. 1998.

<sup>69</sup> Arno, P.S., Levine, C. & Memmott, M.M. The Economic Value of Informal Caregiving. *Health Affairs*, 18:182-188. 1999.

<sup>70</sup> Spector, W.D., et al. *The Characteristics of Long-Term Care Users* (AHRQ Publication No. 00-0049). Agency for Healthcare Research and Policy, Rockville, MD. 2000.

- Characteristics of Caregivers based on the Survey of Income and Program Participation (SIPP)<sup>71</sup>

It is important to recognize that these studies were focusing on different aspects of caregiving, each study had its own methodology and data sources, and thus certain results vary from study to study. Also of note, these studies pertained to different sub-populations of caregivers and differed substantially with regard to the study participant inclusion criteria, such as the ages of care recipients. For example, the *Characteristics of Long-Term Care Users and Informal Caregiving: Compassion in Action, Part II* studies focused on caregiving to care recipients ages 65 and older; whereas the two parts of the widely cited Economic Value of Informal Caregiving study examined caregiving to care recipients ages 15+ and 18+. These distinctions are important, as they have implications for generalizability of the studies' findings and any statistics derived from them.

## CAREGIVING IN THE U.S. (1997)

"Caregiving in the U.S." is a landmark report that was published in 1997 by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP). This report is based on data from a random sample of households.

This widely referenced report estimated that **22.4 million households** involved in caregiving in the U.S. at that time.

This study used the following **definition of caregiving**:

- Caring for persons over the age of 50
- Care occurring some time within the past 12 months
- For persons with limitations in their ADL's (Activities of Daily Living) and/or IADL's (Instrumental Activities of Daily Living)

## THE ECONOMIC VALUE OF CAREGIVING (1998)

In 1998, Peter Arno, Ph.D., and his colleagues published results of their analysis on the economic value of caregiver services. They estimated that caregiver contributions for unpaid labor and services amount to approximately \$196 billion a year, which is an estimate that is widely quoted.

To develop this estimate, Dr. Arno calculated the number of individual caregivers, as opposed to households in the US. He based his mid-range estimate of **25.8 million caregivers** on data from the National Survey of Families and Households (NSFH) for 1987 and 1988 and the Survey of Income and Program Participation (SIPP) for 1986. These data were projected forward to 1997.

This study used the following **definition of caregiving**:

- Caring for persons at least 15 years of age (SIPP) or 18 years of age (NSFH)
- Providing personal care
- For persons needing assistance because of a health condition (SIPP) or disability or chronic illness (NSFH).

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<sup>71</sup> Alecxih, L.M.B., Zeruld, S. & Olearczyk, B. *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. The Lewin Group, Falls Church, VA. [National Family Caregiver Support Program: Selected Issue Briefs.] 2001.



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## INFORMAL CAREGIVING: COMPASSION IN ACTION (1998)

"Informal Caregiving: Compassion in Action," which was published in 1998 by the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration on Aging of the U.S. Department of Health and Human Services, is another landmark report on caregiving.

The data analysis in this study had two parts. Part I analyzed data on "informal" care from the National Survey of Families and Households, NSFH (1987 and 1992). This analysis resulted in an estimate of **52 million caregivers** (31% of the adult population age 20-75) who during the course of any year provide unpaid care to a family member or friend who is ill or disabled.

Part I of the study used the following **definition of caregiving**:

- Caring for persons ages 20 or older
- Providing "informal care" to a family member or friend of any age who is ill or disabled.

Part II looked at a more specific population of caregivers, namely caregivers caring for persons ages 65 and older who needed assistance with everyday activities. This analysis resulted in an estimate of **7 million caregivers** who during the course of any year provide care to a persons aged 65 years old or older.

Part II of the study used the following **definition of caregiving**:

- Caring for persons ages 65 or older
- Providing assistance with everyday activities to a care recipient.

## NATIONAL FAMILY CAREGIVERS ASSOCIATION SURVEY (2000)

In 2000, the National Family Caregivers Association (NFCA) published a report which stated that, during the year prior to the study, **54 million people** had been a caregiver and provided some level of caregiving. This number, which was slightly greater than a U.S. government estimate, was based on random sample survey research.

The **definition of caregiving** used in this research effort, which asked questions of adults over the age of 18, included:

- Caring for persons of all ages
- Providing care (interpretation of the term care was left to the respondent)
- Care occurring some time within the 12 months prior to the study
- Care was provided to the care recipient because of a disability or chronic illness or because of the consequences of old age.

## CAREGIVING IN THE U.S. (2004)

"Caregiving in the U.S., 2004" is the most recent landmark report that was put together and published by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP), based on data from a random sample of households.

This report estimates that there are **44.4 million caregivers** (21% of the adult population), residing in 22.9 million households (21% of U.S. households) provided unpaid care to an adult ages 18 or older.

The study used the following **definition of caregiving**:

- 
- Caring for persons ages 18 or older
  - Care occurring some time within the past 12 months
  - For persons with limitations in their ADL's (Activities of Daily Living) or IADL's (Instrumental Activities of Daily Living).

Another important source of data on caregivers is the **Behavioral Risk Factor Surveillance System (BRFSS)** conducted by the CDC in partnership with all the states. In 2000, the U.S. Administration on Aging (AoA) sponsored two questions pertaining to caregiving to be included in the BRFSS in each state that year.

The first question aimed at estimating percent and number of adults who are providing care to a person age 60 or older:

*"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?" [Yes; No]*

The second question was to find out whom people would call if an older friend or relative needed assistance:

*"Who would you call to arrange short or long-term care in the home for an elderly relative or friend who was no longer able to care for themselves?" [Relative/friend; Would provide care myself; Nursing home; Home health service; Personal physician; Area Agency on Aging; Hospice; Hospital nurse; Minister/priest/rabbi; Other; Don't know who to call]*

The BRFSS source of data is of particular importance since it is the only source, of all national ones, that actually has sufficient sample size to compute estimates for Hawaii, Hawaii's four counties, and to compare those to the national estimates obtained following the same methodology.

## HAWAII SOURCES

Data on caregivers in Hawaii is extremely sparse. This scarcity of local information parallels considerable lack of data on caregivers nationally as well. Only in 2000 did the U.S. Administration on Aging add several questions on caregiving to the Behavioral Risk Factor Surveillance System (BRFSS), the nation's primary public health surveillance survey. Other national estimates on caregivers are all based on specific studies, with Hawaii, being the "small" state, not included in these estimates.

To date, there are two sources of population based, representative data on caregivers in Hawaii:

- Behavioral Risk Factor Surveillance System (BRFSS), year 2000
- Hawaii Health Survey (HHS), year 2003

both coordinated by the Hawaii State Department of Health.

Also, the Executive Office on Aging is sponsoring an extensive list of questions on caregiving that are included in the Hawaii Health Survey 2004, with these data to be available in Spring 2005.

### BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS), YEAR 2000

As described above, in 2000, the U.S. Administration on Aging sponsored two questions pertaining to caregiving that were asked in each state as part of the BRFSS for that year. This source provides population-based, representative data on caregivers in Hawaii and allows comparison with national estimates.

### HAWAII HEALTH SURVEY (HHS), YEAR 2003

The EOA sponsored three questions on family caregiving in the HHS 2003.

The first question on the HHS 2003 was the same as the question sponsored by the U.S. Administration on Aging on BRFSS 2000, as this is a nationally validated question, which allows for benchmarking against national statistics as well as comparisons to the estimates for the year 2000:

*"There are situations where people provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?"*

The second question was,

*"Does this person live with you?"*

that was asked of those who answered affirmatively to the first question.

The third question was,

*"What is your relationship to the person you care for?"*

that was asked of those who answered affirmatively to the first question and when the care recipient lived in the same household.

It is important to recognize certain issues in **interpretability of the data** from the caregiver questions that were asked on the BRFSS 2000 and HHS 2003 surveys. It has been recognized nationally that the terms used in the BRFSS question about family caregiving are not clearly defined and are subject to high variability in interpretation. "There are situations where people provide **regular care** or **assistance** to a family member or friend who is elderly or has a **long-term illness or disability**. During the past month, did you provide any such care or assistance to a family member or friend who is 60 years of age or older?" The terms "regular care" or "assistance" and the terms "long-term illness or disability" are not defined. Respondents may interpret these terms differently.

Additional data on special topics pertaining to sub-groups of the caregiver population are available from several Hawaii studies, including *Statewide Survey on Caregiving* (2002), *A Framework for Family Caregiver Support in Hawaii* (2001), and *Caring for Elderly Family Members; The Impact on Employed Caregivers* (1990). The methodology, particularly the sampling approach, used in these studies limits the extent to which their findings can be generalized to the entire population. These studies are not used in this report.

## HAWAII BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)

The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone survey of adults living in private households, conducted yearly in all states of the United States. The BRFSS is a cooperative agreement with the federal Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services and all states, the District of Columbia, and three U.S. territories. It is designed and conducted to collect information about health status, health behaviors and use of health services. The core questions are developed by the CDC and are asked each year by all states. The optional questions are sponsored by different federal and state agencies and may vary from state to state and year to year. Data are used to determine priority health issues, develop strategic plans, and identify appropriate target populations, monitor the effectiveness of interventions, and support appropriate policies. The Hawaii BRFSS is the annual survey conducted by the State of Hawaii, Department of Health.

## HAWAII HEALTH SURVEY (HHS)

The Hawaii Health Survey (HHS) was developed by the Hawaii Department of Health (DOH) as a cost-effective way to improve the availability of useful information to State health policy makers. The principal objective of the survey is to provide statewide estimates of population parameters that describe: (1) the current health status of the population; (2) access to and utilization of health care; and (3) the distribution of the population by age, sex, and ethnicity. The Hawaii Health Survey is administered by the State of Hawaii, Department of Health, Office of Health Status Monitoring (OHSM). The HHS is a telephone interview survey administered to adult residents in more than 4,000 households each year.

The current survey instrument is modeled after the National Household Interview Survey (NHIS) conducted by the National Center for Health Statistics (NCHS). All survey respondents are adult residents of the State of Hawaii. Data are collected on all members of sample households, and analysis systems include provisions for handling hierarchical files, including complex data weighting. The survey has been expanded over the years, in size and content, to serve additional clients including the DOH Family Health Services Division, Papa Ola Lokahi, the DOH Mental Health Division, the University of Hawaii School of Medicine, Queen's Health Systems, Kamehameha Schools, and many others.

## STAGES IN CAREGIVING FROM CAREGIVER PERSPECTIVE<sup>72,73</sup>

STAGE	DESCRIPTION
<b>I. Performing caregiving tasks</b>	When a dependency situation emerges in which a family member or close acquaintance performs tasks designed to assist an older individual with routine activities previously performed without assistance.
<b>II. Self-definition as a caregiver</b>	When individuals come to view themselves as caregivers and incorporate this activity onto their social or personal identity.
<b>III. Performing personal care</b>	When the caregiver begins providing personal care such as assistance with bathing, dressing, bladder and bowel evacuation, or other aspects of personal hygiene. Whereas the need for personal care marks the end of informal caregiving for many children, it often signals an unambiguous start of caregiving for spouses.
<b>IV. Seeking assistance and formal service use</b>	When the caregiver actively seeks out formal support services designed to assist informal caregivers. The frequent observation that many support services go unused likely reflects the fact that the services have been targeted to caregivers who have not yet reached this stage, which can be considered the "servable" moment.
<b>V. Consideration of nursing home placement</b>	When the caregiver seriously considers placing the elder into a nursing home as an alternative to informal caregiving. When caregivers fail to seek services prior to seriously considering nursing home placement, there is little opportunity for services to play a preventive role.
<b>VI. Institutionalization</b>	When nursing home placement occurs. As many dependent elders die without ever residing in a nursing home, not all caregivers reach this stage.
<b>VII. Termination of the caregiving role</b>	When caregiving has an explicit end. There are three possible reasons: 1) death of the elder (or caregiver); 2) recovery of the elder; or 3) termination of the caregiving role (i.e.—caregiver quits). The significance of this stage is that it acknowledges that care by informal caregivers continues to be provided after the elder has been institutionalized.

<sup>72</sup> Montgomery, R.J.V., & Hatch L. *The Feasibility of Volunteers and Families Forming a Partnership for Caregiving*. In Brubaker T (Ed.), *Family and Long-term Care* (pp. 143-161). 1997. Beverly Hills, CA: Sage Publications.

<sup>73</sup> Pearlin, L.I. The Careers of Caregivers. *The Gerontologist*, 32:647. 1992.

## GLOSSARY<sup>74</sup>

**ACTIVITIES OF DAILY LIVING (ADLs)** - personal care activities necessary for daily living, such as oral hygiene, dressing , toileting, transferring between bed and chair, eating and bathing.

**ADULT DAY CARE/SERVICES** - a respite care service provided outside the home, designed to meet individual needs and support independence and abilities.

**ADVANCED DIRECTIVES** - written documents, signed while a person is competent to make decision(s) about instructions stated in the document.

**AGING IN PLACE** - meeting a person's increasing needs in his/her preferred familiar residence.

**ANXIETY** - feelings of worry, fear, uneasiness, or helplessness possibly caused by many factors.

**ASSISTED LIVING FACILITIES** - residential care settings combining housing, personalized supportive services and health care.

**ASSESSMENT** - the evaluation, usually of mental, emotional and social status to determine an individual's abilities. Its objectives may be diagnostic—to update a care plan or solve a particular situation.

**AUTONOMY** - the ability to make independent decisions or choices, hopefully retained or involved by a care recipient as one's ability permits.

**BURNOUT** - the feeling of becoming overly frustrated and negative often experienced by some caregivers.

**BURDEN** - the impact or consequence of having the responsibility of caring for someone (most frequently with dementia).

**CAREGIVER** - person(s), often one or more relative(s), who provide assistance (in activities and interaction within the environment) to those who are dependent on others for such assistance.

**CARE PLAN** - a written action plan which contains the strategies for delivering care to address individual's needs and problems.

**CASE/CARE MANAGEMENT** - a formal service usually consisting of assessment, arrangement, and coordination of services. Care management and coordination are informal terms. However, case management usually implies a comprehensive assessment, the development of a care plan, evaluating the services, and reassessing the situation. A social worker, nurse, or gerontologist may provide such services.

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<sup>74</sup> Many of these terms and definitions have been adopted with modifications from: Alzheimer's Disease and Related Disorders Association, Inc.; Patient and Family Services. *Terms and Tips*. 1995.

**CARE RECEIVER/RECIPIENT** - a person who may be dependent on another(s) for care in activities and interaction within the environment.

**CHRONIC ILLNESS** - an illness which lasts over an extended period of time and is treated by management rather than with the expectation of a cure.

**CO-EXISTING ILLNESS** - a medical condition or illness that occurs simultaneously with another condition or illness, which may complicate or obscure diagnosis or treatment of each.

**COGNITIVE FUNCTION** - describes the way information is processed in the brain with such functions as judgment, memory, perception, etc.

**COMPETENCE** - usually used in a legal sense, refers to a person's ability to understand information, make an informed choice based on the information and values, and communicate that decision.

**CONTINUUM OF CARE** - encompasses a continuous, inseparable court of care over various care services and their locations of services considered necessary over the full course of an illness.

**DEMENTIA** - a significant loss of cognitive functions such as thinking and memory, which interferes with an individual's daily function and everyday life; it may be caused by many different disorders.

**DEPRESSION** - a prolonged mood disturbance that affects self-worth, outlook, and living; it is capable of cure or improvement and should be diagnosed by a capable professional.

**ESTATE PLANNING** - thoughtful consideration and planning, usually legal, for an individual's future in the area of finances and property; in some cases planning for health care decisions may begin at this time.

**FUNCTIONAL STATUS/CAPABILITIES** - the measurement (usually through a scale or instrument of assessment) of a person's abilities in activities of daily living and/or instrumental activities of daily living.

**GUARDIAN** - a legal term for a person who is lawfully vested with the care of the property and/or person who is legally incompetent.

**HOSPICE** - a philosophy and approach to care for individuals who are terminally ill. This care is palliative or comfort oriented and assists the family and individuals with their emotional, physical, social, and spiritual needs.

**INFORMED CONSENT** - a legal term referring to the disclosure and consideration of all relevant facts available on which to base an intelligent decision and consent to a particular medical treatment.

**INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs)** - secondary level of activities of daily living such as cooking, cleaning, shopping, driving, transportation, etc.

**LIFE EXPECTANCY** - the age to which a given person or population is anticipated to live based on survival statistics.

**LIFE SPAN** - the maximum projected age to which a given person or population is anticipated to live.

**LONG-TERM CARE** - the extended care (usually outside the home) of an individual who is dependent on others for his/her needs. This term usually implies nursing home care administered over a prolonged period of time.

**MEDICAID** - a federal-state program administered by states to provide health care and services for low-income individuals.

**MEDICARE** - a federal health insurance program (whose aim is to protect against health care costs, but does not cover all medical expenses nor long term care) for persons over 65 years, particular disabled persons under 65 years and those of any age who have permanent kidney failure.

**MEMORY IMPAIRMENT** - damage in the brain that interferes with memory processes. This damage may be attributable to numerous conditions, disease or accidents.

**NURSING HOME** - an institutional setting that offers 24-hour supervision and care to individuals, usually older persons, who are no longer able to be responsible for themselves in an independent living setting.

**OMBUDSMAN** - an advocate, designated by a government agency to promote the quality of the delivery of governmental services; the Executive Office on Aging has an Ombudsman to promote quality of care in nursing facilities.

**PACING/WANDERING** - walking about, either purposefully in a pattern, and/or randomly in motion.

**PERSONAL CARE** - assistance with intimate activities (such as grooming, bathing, eating, dressing, etc.) of daily living.

**PREVALENCE** - proportion of people in the population who have a certain disease or characteristic at a certain point in time. For example, prevalence of caregiving of 12% among adults aged 18 years old and older means that 12% of adults aged 18 and over are caregivers.

**PROFESSIONAL EDUCATION** - education on a focused subject for professionals, perhaps with some accreditation process for different disciplines.

**PUBLIC AWARENESS** - information in a focused area broadly disseminated throughout the community.

**REIMBURSEMENT** - financial reimbursement for costs incurred by individuals in the care of their loved one.

**RESEARCH** - study, collection of data, and analysis based on hypotheses regarding a focused topic. It may involve laboratory or clinical study, social and behavioral scrutiny or programmatic evaluation.

**RETIREMENT/ LEISURE PLANNING** - consideration of and preparation for an individual's use of time and resources after retiring from work.



**RETIREMENT COMMUNITY** - a group of single or multiple unit residences that are marketed to and utilized by predominately older adults who are retired. Some may be age-restricted. There are often business and retailing amenities and diverse organized interest groups to make the community self sufficient.

**RIGHT-TO-DIE** - a person's individual medical care choices that impact the end of life. These rights relate to competency, and considerations should include appropriate assessment, advanced directives, quality of life and a supportive environment.

**RIGHTS** - good and natural expectations that may or may not be assured by law.

**SENILE** - refers to old age and since originally used to describe older persons who were Dementing, it is often used in place of dementia. Senility encompasses a collection of symptoms that may be caused by a host of different disease processes or conditions.

**SHARED RISK** - a negotiated agreement between a care provider, a cognitively impaired person and the family in an attempt to balance autonomy and safety without overprotecting the individual.

**SKILLED NURSING FACILITY** - provides skilled nursing care and related services for residents who require medical or nursing care, rehabilitation services for injured, disabled, or sick persons, and health-related care and services above the level of board and room and not primarily for the care and treatment of mental diseases.

**SUPPORT GROUP** - a formal gathering of persons sharing common interests and issues. The participants and facilitators share information, mutual support and often exchange coping skills with one another.

**SUPPORTIVE HOUSING** - alternative residential care setting (other than skilled nursing facilities) that link housing and services. These may be licensed or unlicensed by the State.

**SURROGATE** - a substitute who makes decisions for someone who is no longer capable of making decisions for him/herself. The surrogate may be appointed as guardian or conservator by a court or identified when the person is competent through a power of attorney process.

**THERAPY** - a treatment or intervention intended to change an outcome or course of disease.

**TRANSPORTATION** - provision of transportation to and/or from a service often arranged through an agency or organization.



*"E Loa Ke Ola"  
May Life Be Long*

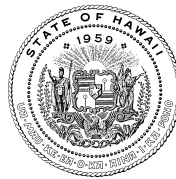
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